Understanding advanced (metastatic) prostate cancer

About this booklet

This booklet is about advanced prostate cancer. It is for anyone who has been diagnosed with advanced prostate cancer. There is also information for carers, family members and friends.

The booklet explains the symptoms of advanced prostate cancer, and how it is diagnosed and treated. It also has information about emotional, practical and financial issues.

We hope it helps you deal with some of the questions or feelings you may have. We cannot give advice about the best treatment for you. You should talk to your doctor, who knows your medical history.

How to use this booklet

This booklet is split into sections to help you find what you need. You do not have to read it from start to finish. You can use the contents list on page 3 to help you.

It is fine to skip parts of the booklet. You can always come back to them when you feel ready.

On pages 135 to 143, there are details of other organisations that can help.

There is also space to write down questions and notes for your doctor or nurse (pages 145 to 146).

Quotes

In this booklet, we have included quotes from people who have had advanced prostate cancer, which you may find helpful. These are from people who have chosen to share their story with us. To share your experience, visit **macmillan.org.uk/shareyourstory**

For more information

If you have more questions or would like to talk to someone, call the Macmillan Support Line free on **0808 808 00 00**, 7 days a week, 8am to 8pm, or visit **macmillan.org.uk**

If you would prefer to speak to us in another language, interpreters are available. Please tell us, in English, the language you want to use.

If you are deaf or hard of hearing, call us using Relay UK on **18001 0808 808 00 00**, or use the Relay UK app.

We have some information in different languages and formats, including audio, interactive PDFs, easy read, Braille, large print and translations. To order these, visit **macmillan.org.uk/otherformats** or call **0808 808 00 00**.

Contents

THE PROSTATE AND PROSTATE CANCER

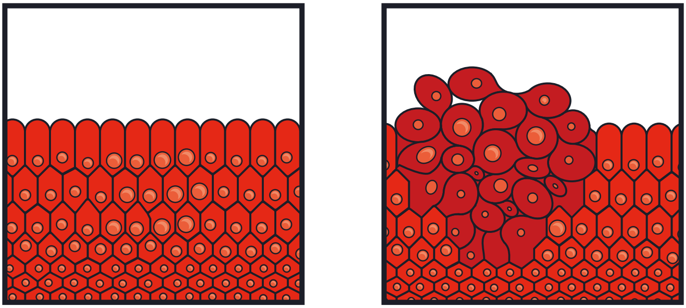
What is cancer?

Cancer starts in cells in our body. Cells are tiny building blocks that make up the organs and tissues of our bodies. They divide to make new cells in a controlled way. This is how our bodies grow, heal and repair. Cells receive signals from the body telling them when to divide and grow and when to stop growing. When a cell is no longer needed or cannot be repaired, it gets a signal to stop working and die.

Cancer develops when the normal workings of a cell go wrong and the cell becomes abnormal. The abnormal cell keeps dividing making more and more abnormal cells. These eventually form a lump (tumour). Not all lumps are cancerous. Doctors can tell if a lump is cancerous by removing a small sample of tissue or cells from it. This is called a biopsy. The doctors examine the sample under a microscope to look for cancer cells.

A lump that is not cancerous (benign) may grow but cannot spread to anywhere else in the body. It usually only causes problems if it puts pressure on nearby organs.

Cells forming a tumour



Normal cells

Cells forming a tumour

A lump that is cancer (malignant) can grow into nearby tissue. Sometimes, cancer cells spread from where the cancer first started (the primary site) to other parts of the body. They can travel through the blood or lymphatic system. When the cells reach another part of the body, they may begin to grow and form another tumour. This is called a secondary cancer or a metastasis.

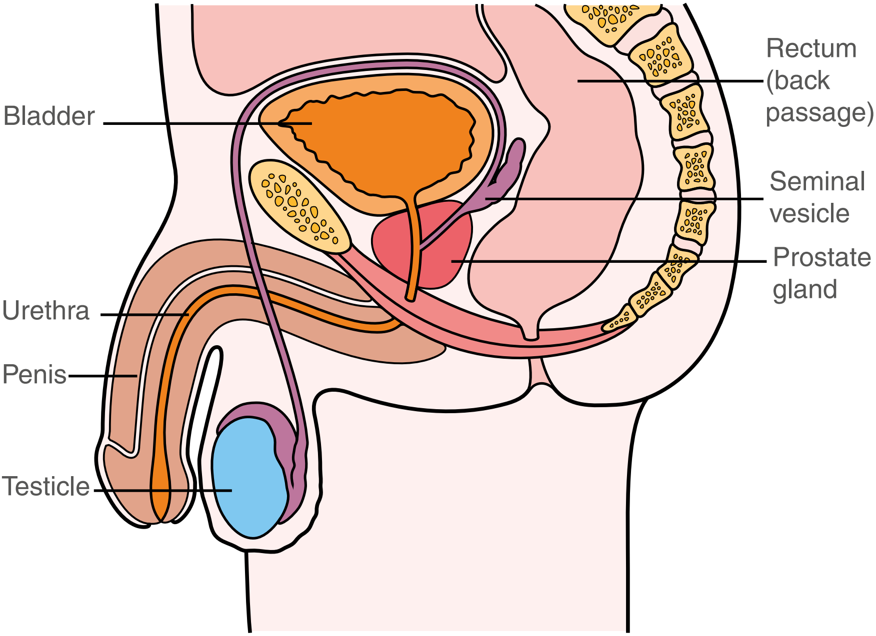
The prostate

The prostate is a small gland about the size of a walnut. It is divided into 2 lobes and surrounded by an outer layer called the capsule. The prostate gets bigger as you get older.

The prostate is below the bladder, surrounding the first part of a tube called the urethra. The urethra carries pee (urine) from the bladder to the penis. The same tube also carries semen, which is the fluid containing sperm. Just behind the prostate is the back passage (rectum). There are also some lymph nodes (sometimes called glands) near the prostate (page 10).

The prostate contains muscle tissue and glandular tissue. Glandular tissue releases (secretes) certain substances.

The prostate



What does the prostate do?

The prostate produces a fluid that mixes with sperm from the testicles to make semen. This fluid is stored in 2 tube-shaped glands called the seminal vesicles. They are found situated just behind the bladder. During sex, the muscle tissue helps force (ejaculate) prostate fluid and sperm into the urethra.

The sex hormone testosterone is made by the testicles. It controls how the prostate works. Testosterone is responsible for things like your sex drive, getting an erection, and muscle development.

The prostate also produces a protein called prostate-specific antigen (PSA). This helps to make semen more watery. A blood test can measure PSA. This is called a PSA test. Doctors use it to help diagnose different prostate problems, including cancer.

We have more information about PSA tests at **macmillan.org.uk**

If you are a transgender woman

People who have a prostate include men, transgender (trans) women and people assigned male at birth. If you are a trans woman and have had genital gender-affirming surgery as part of your transition, you still have a prostate.

It is important to talk to your GP or nurse if you are worried about prostate cancer or have symptoms.

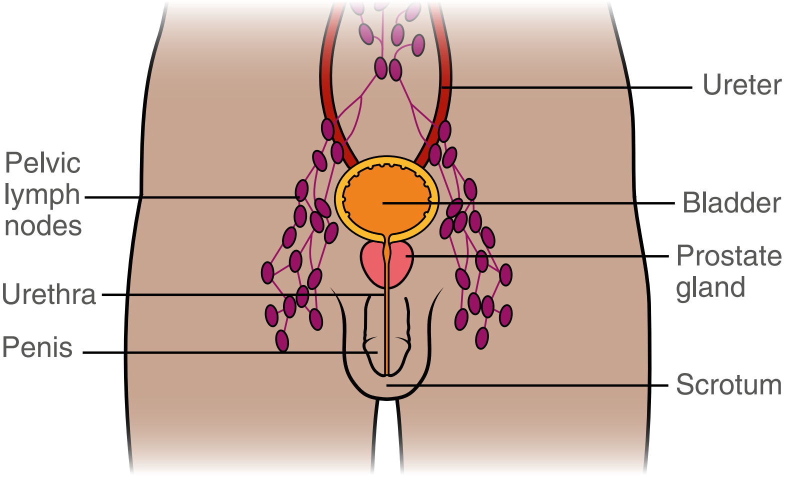
The lymphatic system

The lymphatic system helps protect us from infection and disease. It also drains lymph fluid from the tissues of the body before returning it to the blood. The lymphatic system is made up of fine tubes called lymphatic vessels that connect to groups of lymph nodes throughout the body.

Lymph nodes are sometimes called lymph glands. They filter bacteria (germs) and disease from the lymph fluid. When you have an infection, some lymph nodes may swell as they fight the infection.

In advanced prostate cancer, there are usually cancer cells in the lymph nodes close to the prostate and in lymph nodes further away.

Prostate lymph nodes



Advanced prostate cancer

Prostate cancer is one of the most common cancers in the UK. It is more common over the age of 65. Prostate cancer can happen in younger people, but it is uncommon in people aged under 50.

Advanced prostate cancer is when the cancer cells have spread from the prostate to other parts of the body. It is not possible to cure advanced prostate cancer. But there are treatments that can help to control it (pages 37 to 85).

The most common place for prostate cancer to spread to is the bones. It may also spread to lymph nodes outside the pelvis, or to the liver or the lungs.

Advanced prostate cancer may develop in people who have previously been treated for prostate cancer. This may be many years later. Sometimes, prostate cancer has already spread to other parts of the body when it is first diagnosed.

The cancer cells usually spread through the blood or through the lymphatic system (page 10). When the cancer cells reach a new area of the body, they keep dividing and form another cancer. This is called a secondary cancer or metastasis.
But it is still prostate cancer.

If you are a trans (transgender) woman or are non-binary or assigned male at birth, you also need to be aware of prostate cancer. Advanced prostate cancer may affect trans women, but there is not enough evidence to know how common this is.

Prostate Cancer UK has detailed information about trans women and prostate cancer (page 135). The LGBT Foundation can also give you confidential advice and support (page 142).

You can also talk to one of our cancer support specialists (page 132).

Risk factors and causes

Doctors do not know the exact causes of prostate cancer. But there are risk factors that can increase the chance of developing it. Having one or more risk factors does not mean you will get prostate cancer. There are different risk factors that may affect the risk of getting prostate cancer.

Age

This is the strongest risk factor for prostate cancer and your risk increases from the age of 50. It is uncommon under the age of 50 and more common over the age of 75. Risk factors like ethnicity and family history are linked with getting prostate cancer at a younger age.

Ethnicity

If you are Black, you have a much higher risk of developing prostate cancer. The reason for this is not clear, but it may be because of genetic factors. You are also more likely to develop prostate cancer at a younger age.

If you are Black and aged 45 or over, Prostate Cancer UK has more information for you about your risk (page 135). It gives advice on talking to your GP about your risk of getting prostate cancer and helps you to make decisions about having a PSA test (page 23).

If you are Asian, your risk of prostate cancer is much lower. We do not know why this is.

Family history

Sometimes there may be a possible family link (inherited). The risk of prostate cancer is higher if you have:

- either a father or brother who had prostate cancer – the risk is greater if they were diagnosed under the age of 60
- 2 or more close relatives (father, brother, grandfather, half-brother, uncle) on the same side of the family who had prostate cancer
- a mother who has had breast cancer
- inherited certain cancer gene changes (mutations).

We get a copy of each of our genes from both parents. Genes are the instructions that tell our cells what to do. Doctors think 5 to 10 out of 100 prostate cancers (5% to 10%) are linked to inherited gene changes.

Rarely, prostate cancer may be linked to changes in certain genes. They are called BRCA1 and BRCA2. These altered genes increase the risk of breast and ovarian cancer in women. If you have inherited the BRCA2 gene change, your risk of prostate cancer is 5 times higher. The BRCA1 gene may also increase risk, but this is not as clear.

Prostate cancer risk is also higher if you have Lynch syndrome. Lynch syndrome is also called hereditary non-polyposis colorectal cancer (HNPCC). Lynch syndrome is rare but can increase the risk of a number of cancers.

Talk to your GP if you have a family history of cancer and are worried about your risk of prostate cancer.

We have more information about family history and cancer in our booklet **Cancer genetics – how cancer sometimes runs in families** (page 130).

Body weight and diet

Being very overweight (obese) may increase the risk of having a more advanced prostate cancer. It may also increase the risk of having a faster-growing type of prostate cancer (pages 30 to 34).

Eating a balanced diet and doing regular physical activity will keep you to a healthy weight. Our booklets **Healthy eating and cancer** and **Physical activity and cancer** have more information (page 130).

> **‘I had been getting pains in my lower abdomen when I did something slightly strenuous, like taking the dogs for a walk. I had been getting fatigued quicker than normal.’**
>
> **Steven, diagnosed with advanced prostate cancer**

Symptoms of advanced prostate cancer

Prostate cancer often grows slowly. Symptoms may not develop for many years. The symptoms of advanced prostate cancer may be caused by an enlarged prostate (pages 8 to 9).

Symptoms of an enlarged prostate can include:

- needing to pee (pass urine) more often than usual, especially at night
- difficulty peeing – for example, a weak flow or having to strain to start peeing
- feeling like you have not completely emptied your bladder afterwards
- an urgent need to pee
- blood in your pee or semen
- rarely, pain when peeing or ejaculating.

Symptoms of advanced prostate cancer may also be caused by the cancer spreading to another part of the body. This is called secondary cancer. The symptoms will depend on which part of the body is affected. But after the lymph nodes, the most common place for prostate cancer to spread to is the bones.

Symptoms may include:

- being more tired than usual
- generally feeling unwell
- having less of an appetite
- losing weight for no obvious reason.

If you have any of the symptoms we mention here, it is important to have them checked by your doctor.

Secondary cancer in the bones

Prostate cancer may spread to bones, such as the:

- spine
- pelvis
- thigh bone (femur)
- ribs.

It may affect different areas of the bones rather than only one area.

Pain

The first sign of a secondary cancer in the bones is usually an ache in the bone. This is often in the hips or in the back. The pain gradually gets worse over a few weeks. You may have pain during the day but also at night. This can make it difficult to sleep. You usually need to take painkillers to help you.

Other types of pain that are not caused by cancer may feel different. For example, pain from arthritis is often worse early in the morning and is not there all the time. Talk to your doctor or specialist about pain if you are unsure.

A secondary cancer in the bone may gradually make the bone weaker. Bones that are very weak may break (fracture) more easily. There are treatments you can have to help strengthen the bones and reduce pain.

Our booklet **Understanding secondary cancer in the bone** has more information (page 130).

Spinal cord compression

If the bones in the spine have cancer in them, the cancer may press on the spinal cord. This is called spinal cord compression.

It usually affects your legs and may cause:

- pain
- weakness
- numbness or tingling in your legs.

Spinal cord compression is not common. But if you notice these symptoms, you should contact your doctors straight away – even at the weekend or during a holiday period. If you cannot contact your GP or cancer doctor, you should go to the nearest emergency department (A&E). We have more information in our leaflet **Metastatic spinal cord compression** (page 130).

Anaemia

Prostate cancer can sometimes spread from the bone to the bone marrow. Bone marrow is the spongy material in the middle of our bones where our blood cells are made. This includes red blood cells, which carry oxygen around the body. If the bone marrow cannot produce enough red blood cells, you may become anaemic. This can make you feel very tired and breathless, and you may look very pale.

Other symptoms

Prostate cancer can sometimes spread to other parts of the body, such as the lymph nodes, lungs or liver. If you notice any new symptoms that last for 2 weeks or more, you should talk to your cancer doctor.

It is important to remember that any of the symptoms mentioned here can be caused by problems other than cancer.

DIAGNOSING ADVANCED PROSTATE CANCER

How advanced prostate cancer is diagnosed

How you are diagnosed with advanced prostate cancer will depend on your situation. It may be:

- after previous treatment for early or locally advanced prostate cancer – possibly many years ago
- after being diagnosed with cancer in the prostate, if further tests show the cancer is advanced
- after tests to check symptoms of bone pain, with no previous diagnosis of prostate cancer.

The most common places for prostate cancer to spread to are the bones and lymph nodes outside the pelvis (page 10). It sometimes spreads to areas such as the lungs or liver.

Tests

Your doctor or specialist nurse will explain the tests you will have. You may not need all the tests we mention here. If you have, or have had, prostate cancer and have symptoms, you will have tests to see if the cancer has spread. These usually include a PSA test and bone scan (page 24).

If you have just been diagnosed with prostate cancer, you will have further tests to see if the cancer is advanced. These include a bone scan, a CT scan or an MRI scan.

If you were diagnosed with secondary cancer in the bones, you will need tests to find out if it started in the prostate. We have more information in our booklet **Understanding secondary cancer in the bone** (page 130).

PSA test

Your doctors take a blood sample to check the level of PSA (prostate-specific antigen) in your blood. PSA is a protein made in the prostate. Some of this PSA leaks into the blood and can be measured in the PSA test.

Prostate cancer often causes a raised level of PSA. But the test is not always reliable, and a raised level of PSA does not mean you have prostate cancer. This is because as you get older the level of PSA in the blood rises slowly. Different things can increase PSA levels. But most people with advanced prostate cancer will have a very high PSA level.

If you have had prostate cancer before, you will have regular blood tests to check your PSA levels. Visit **macmillan.org.uk** for more information about PSA tests.

Biopsy

You may be offered a biopsy of the prostate. This involves a doctor removing samples of prostate tissue with a fine needle. A pathologist (a doctor who is an expert in studying cells) looks at the samples under the microscope to check for cancer.

If you have a very high PSA or scans show the cancer has spread, you may not need a biopsy.

You may have a biopsy from the area of the secondary cancer. This is to find out if it is cancer and what type it is. This only happens if you have not been diagnosed with prostate cancer before.

Biopsies are sometimes used to decide whether targeted therapies may be suitable for you.

X-rays

You may have x-rays of the bones in a painful area to find out if there are any abnormal areas.

Bone scan

This scan uses a low dose of radiation to show abnormal areas of bone. Abnormal bone absorbs more radioactivity than normal bone, so it shows up on the scan pictures.

Abnormal areas of bone seen on the scan are sometimes called hot spots. Hot spots are not always cancer that has spread to the bones. They may be changes to the bone caused by normal healing or by other health conditions, such as arthritis.

You have the scan in the x-ray department at the hospital.

The person doing the scan is called a radiographer. About 3 hours before the scan, they inject a radioactive substance into a vein, usually in the arm. This substance is called a tracer. Rarely, some people are allergic to it. Tell the radiographer straight away if you feel breathless, sweaty, weak or unwell.

The scan takes about 30 to 60 minutes. You lie on a narrow bed. The bed moves slowly back and forward through the scanner.

You can usually go home after the scan. The amount of radioactive tracer used is small. But you be advised not to have close contact with pregnant women, babies and young children for up to 24 hours after the scan.

MRI (magnetic resonance imaging) scan

An MRI scan uses magnetism to build up a detailed picture of areas of the body. It can be used to look at the prostate and different parts of the body to see if the cancer has spread.

You have the scan in the x-ray department of a hospital. The person who does the scan is called a radiographer. They may give you an injection of dye into a vein. This helps show certain areas of the body more clearly.

You may have an MRI scan before you have a biopsy. Specialised scans called multi-parametric MRI scans give more detailed images of the body. These images give more information about a suspected area of cancer.

Depending on the results of the scan, your doctor may explain that you do not need a biopsy.

CT scan

A CT scan makes a detailed picture of the inside of the body. The picture is built up using x-rays taken by the CT scanner.

The scan uses radiation, but this is very unlikely to harm you. It will not harm anyone you come into contact with.

You have the scan at a hospital. You will get an appointment letter telling you whether you need to do anything before the scan. You should tell the person doing the scan if you are pregnant or think you could be.

You may have a drink or injection of a dye. This is called a contrast. It helps show certain areas of the body more clearly. The contrast may make you feel hot all over for a few minutes. It is important to tell your doctor if you are allergic to iodine or have asthma. This is because you could have a more serious reaction.

The scan is painless. It usually takes 5 to 10 minutes. The scanner looks like a large, thick ring. You lie still on a narrow bed which moves slowly backwards and forwards through the ring.

We have more information about having a CT scan at **macmillan.org.uk/ct-scan**

A CT scanner

PET or PET-CT scan

A PET scan uses a low dose of radiation to check the activity of cells in different parts of the body.

You may have a PET scan and a CT scan together. This is called a PET-CT scan. It can give more detailed information about cancer or abnormal areas seen on other scans.

About 1 hour before the scan, the radiographer will inject a radioactive substance into a vein, usually in your arm. This is called a tracer. The radiographer will encourage you to drink water. This helps move the tracer around your body.

Very rarely, some people are allergic to the tracer. This can make them feel breathless, sweaty or weak. Tell the radiographer straight away if you feel unwell.

The scan takes about 30 to 60 minutes. The scanner looks like a large, thick ring. You lie still on a narrow bed which moves slowly backwards and forwards through the ring.

The amount of radiation used is very small. But the radiographer will advise you not to have close contact with pregnant people, babies and young children for up to 24 hours after the scan.

We have more information about PET and PET-CT scans at **macmillan.org.uk/pet-ct-scan**

Waiting for your results

Waiting for test results can be a difficult time. It may take from a few days to a few weeks for the results of your tests to be ready. Your doctor will tell you the results and talk to you about the best treatment for your situation. Most prostate cancers grow very slowly. Even if it takes a few weeks to get your results, it is unlikely the cancer will change during this time.

People have different support networks. Try to talk to someone you trust about how you are feeling. This could be a family member, partner or friend.

If you feel you have no one to talk to, you can call our cancer support specialists on **0808 808 00 00**, or visit our Online Community where you can speak to other people who understand (page 133).

Staging of prostate cancer

The stage of a cancer describes its size and how far it has spread. The results of your tests help your doctors decide on the stage. You and your doctors can then talk about the best treatment choices for you.

Your doctors also look at the grade of the cancer (pages 33 to 34) to help them plan your treatment. The grade gives an idea of how quickly the cancer might grow or spread.

Doctors often use the TNM staging system or a number staging system for prostate cancer.

TNM staging

This gives information about:

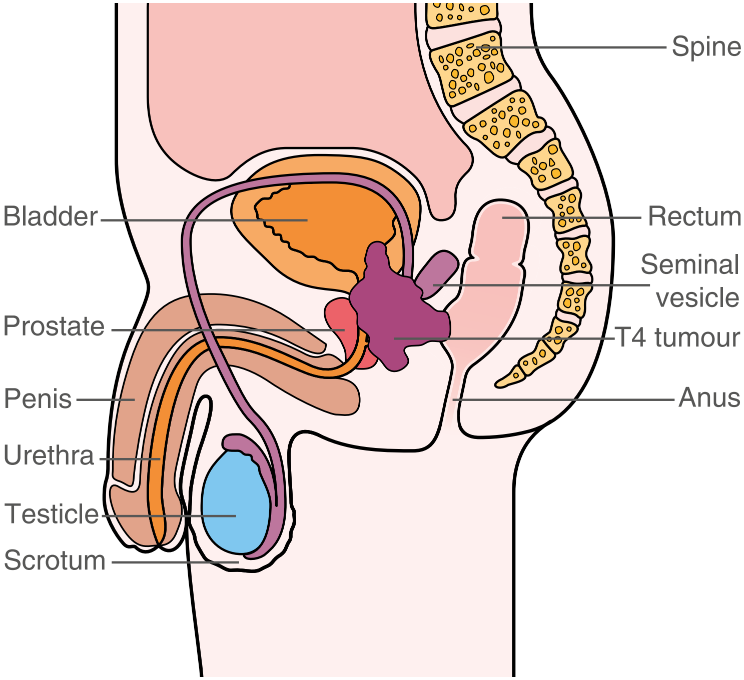
- the tumour (T)
- whether the cancer has spread to any lymph nodes (N)
- whether the cancer has spread to another part of the body, called metastasis (M).

Tumour

Doctors put a number next to the T to describe the size and spread of the cancer.

- T1 and T2 tumours are called early (localised) prostate cancer. They are contained in the prostate.
- T3 tumours have spread outside the prostate and may be growing into tissues or organs close by.
- T4 tumours have spread into areas close by, such as the bladder or back passage (rectum), or the muscle that controls peeing (passing urine).

T4 prostate tumour



Nodes

- N0 means there is no cancer in the lymph nodes near the prostate.
- N1 means there is cancer in 1 or more lymph nodes close by.

Metastasis

- M1 means the cancer has spread to another part of the body. Advanced prostate cancer is always M1.

With the TNM staging system, advanced or metastatic prostate cancer can be any T, any N, but will always be M1.

You can talk to your doctor or specialist nurse about your TNM staging. They can explain it to you.

Number staging system

Number staging brings together different parts of the TNM staging system and gives it a number stage. Advanced or metastatic prostate cancer is always stage 4. But some stage 4 cancers are locally advanced. We have separate information in our booklet **Understanding locally advanced prostate cancer** (page 130).

Stage 4 can be either of the following:

- A T4 tumour that has not spread to the lymph nodes close by, or any tumour that has spread to these nodes. Doctors call this locally advanced prostate cancer.
- Any tumour that may be in the lymph nodes close by and has spread to another part of the body, such as the bones, lymph nodes outside the pelvis, liver or lungs. Doctors call this advanced or metastatic prostate cancer.

Grading of prostate cancer

A doctor decides the grade of the cancer by how the cancer cells look under the microscope. The grade gives an idea of how quickly the cancer might grow or spread.

Gleason score

Gleason is the most commonly used grading system. It looks at the pattern of cancer cells in the prostate. There are 5 different patterns, graded from 1 to 5.

Grade 1 is very similar to normal prostate tissue, and grade 5 is very different to normal tissue. Only grades 3, 4 and 5 are cancer.

There may be more than one grade. The doctor examines all the samples taken at your biopsy to find:

- the most common grade
- the highest grade.

They add these together to get your Gleason score. A Gleason score of 7 could be:

- 3 + 4 – the most common grade is 3 and the highest grade is 4

or

- 4 + 3 – the most common and highest grade are both 4, but there is also some grade 3 present.

What your Gleason score means

If your Gleason score is between 6 and 10, the cancer is one of the following:

- Gleason score 6 – slow growing and less likely to spread.
- Gleason score 7 – intermediate grade (between slow and fast-growing).
- Gleason score 8 to 10 – high grade (more likely to grow quickly and to spread).

Most people with advanced prostate cancer have a high Gleason score. But cancer with a Gleason score of 6 or 7 can sometimes spread to other parts of the body too. Equally, having a high Gleason score does not mean that your cancer is definitely advanced.

> **My original diagnosis was a PSA of 67 with a Gleason score 5 on the right and 4 on the left. I was considered advanced because the cancer had migrated to a lymph node and a seminal vesicle.**
>
> **Paul, diagnosed with advanced prostate cancer**

Your data and the cancer registry

When you are diagnosed with cancer in the UK, some information about you, your cancer diagnosis and your treatment is collected in a cancer registry. This is used to plan and improve health and care services. Your hospital will usually give this information to the registry automatically. There are strict rules to make sure the information is kept safely and securely. It will only be used for your direct care or for health and social care planning and research.

Talk to your doctor or nurse if you have any questions. If you do not want your information included in the registry, you can contact the cancer registry in your country to opt out (page 143).

TREATING ADVANCED PROSTATE CANCER

Treatment overview

When prostate cancer has spread to other parts of the body, such as the bones, you can have treatments to help. Although the cancer cannot be cured, it can be controlled, sometimes for several years. Treatments can also help relieve symptoms and improve your quality of life.

Your doctor and nurse will help you to understand the treatments and how they may affect you. It is a good idea to have a partner, family member or friend with you at the appointment. They can help you remember what was said and talk to you about it afterwards.

Treatments

The main treatments are hormonal therapy, chemotherapy and radiotherapy. You may have a combination of these. Your cancer doctor and nurse will explain the treatments that may be helpful for you. This will depend on:

- your general health
- where the cancer is and the symptoms it is causing
- any previous treatments you have had for prostate cancer
- how treatments and their side effects may affect your everyday life.

Your doctor will help you decide on the right treatment plan for you.

Hormonal therapy

Prostate cancer needs testosterone to grow. Hormonal therapies reduce the amount of testosterone in the body (pages 47 to 59). This may slow the growth of the cancer, or stop it growing for a while.

Hormonal therapy is recommended for most people with advanced prostate cancer. You can have it as injections. You may have 2 types of hormonal therapy at the same time. For example, you might have hormonal injections alongside hormonal tablets. You may have hormonal therapy with chemotherapy or radiotherapy.

Chemotherapy

Chemotherapy uses anti-cancer (cytotoxic) drugs to destroy cancer cells – page 61 to 68. It is usually given when hormonal therapy is no longer controlling the cancer. It is sometimes used in combination with hormonal therapy when you are first diagnosed with advanced prostate cancer.

Radiotherapy

You may have radiotherapy to improve symptoms, such as pain in the prostate area or the bones (pages 70 to 75). Radiotherapy can also help strengthen a weakened bone.

Surgery

Surgery to remove the prostate is not used for advanced prostate cancer. You may have an operation called a transurethral resection of the prostate (TURP) to help problems with peeing (passing urine) – pages 76 to 80.

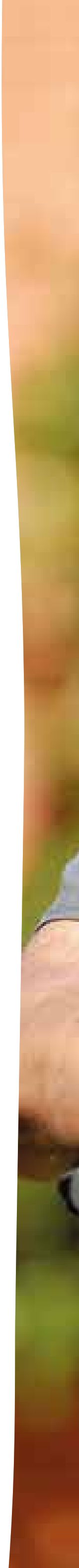
Another type of operation removes part of the testicles. This is called a subcapsular orchidectomy. It is done to reduce the amount of testosterone in the body. It may be used if you are not able to have hormonal therapy injections. Surgery may also be used to help control other symptoms. If you have a bone that is at high risk of breaking, surgery may help to keep the bone stable.

There are other treatments available that can relieve and control any symptoms you may have (pages 17 to 19). We have a video on our website about treating advanced prostate cancer. Visit **macmillan.org.uk/cancer-information-and-support/prostate-cancer/advanced-prostate-cancer**

Specialist nurses called palliative care nurses can also provide help and support. They are experienced in assessing and treating symptoms of advanced cancer. You may meet them when you are at a clinic or in hospital.

There is also support available to help you cope with the emotional effects of cancer and its treatment in the booklet **How are you feeling? The emotional effects of cancer** (page 130).

Your cancer doctor or GP may be able to refer you to a doctor or counsellor who specialises in supporting people with cancer and their families. Our cancer support specialists can also tell you more about support services and counselling in your area (page 132).



How your treatment is planned

After your test results, you and your doctor start to talk about your treatment. Your doctor usually meets with other specialists to get their opinions too.

Multidisciplinary team (MDT) meeting

A team of specialists meet to talk about the best treatment for you. They are called a multidisciplinary team (MDT).

The MDT looks at national treatment guidelines or the latest evidence for the type of cancer you have. If you have any treatment preferences, your doctor will tell the MDT about this.

The MDT will usually include the following professionals:

- Oncologist – a doctor who treats people who have cancer.
- Surgeon – a doctor who does operations (surgery).
- Clinical nurse specialist – a nurse who gives information about cancer, and support during treatment.

The MDT may also include:

- a palliative care doctor – a doctor who helps with symptom control and end-of-life care
- a dietitian
- a physiotherapist
- an occupational therapist (OT)
- a psychologist or counsellor.

Talking about your treatment plan

After the MDT meeting, you will usually see your specialist doctor and nurse. They will talk to you about your treatment plan. It can help to write down your questions before you see them. You may want to ask a family member or friend to come with you. They can help remember what is said and talk with you about it afterwards. You need to know as much as possible before you can make any treatment decisions.

Your specialist doctor should explain:

- the aim of the treatment
- the benefits of the treatment
- the disadvantages of the treatment – for example, the risks and side effects
- any other treatments that may be available
- what may happen if you do not have the treatment.

Cancer treatments can be complex. It can also be hard to concentrate on what you are being told if you are feeling anxious. If the doctor says something you do not understand, ask them to explain it again.

Most people worry about the side effects of treatment. Your doctor or nurse will explain how side effects can be controlled and what you can do to manage them. They can also tell you if your treatment is likely to cause any late effects and how these can be managed.

You may need more than one meeting with your doctor or nurse to talk about your treatment plan.

Benefits and disadvantages of treatments

It is important to know the benefits, possible disadvantages and side effects of treatments before you decide to have them. Your doctor or specialist nurse will explain these to you.

Treatments can help to control the cancer and relieve the symptoms. But there may be a time when the treatment has little effect on the cancer and you have the side effects without any benefits.

Making decisions in these situations is always difficult. You may want to talk about it with your cancer doctor, specialist nurse and family. It may also help to discuss the options with our cancer support specialists on **0808 808 00 00**.

If you decide not to have further treatment, you will be given supportive (palliative) care, with medicines to control any symptoms.

Making treatment decisions

You and your doctor can decide together on the best treatment plan for you. Your doctor is an expert in the best treatments. But you know your preferences and what is important to you. You can decide how involved you want to be in your treatment plan.

Sometimes doctors need to review a treatment plan. This may be when more information about the cancer becomes available – for example, when the doctor knows the results of surgery to remove the cancer. It may mean making more decisions with your doctor. We have more information in our booklet **Making treatment decisions** (page 130).

Giving your permission (consent)

Doctors need your permission (consent) before you have any treatment. They will give you all the information you need to make your decision. We explain this in our section on talking about your treatment plan.

You can give consent in writing when you sign a form that your doctor gives you, agreeing to a treatment. Or it can be a spoken (verbal) agreement with your doctor. Your doctor records your consent in your patient notes.

You may decide not to have treatment even when your doctor advises you to have it. If you refuse treatment, your decision must be respected. But your doctor needs to make sure you have all the information you need to make your decision. You need to understand all your treatment options and what will happen if you do not have the treatment.

Always talk to your doctor about any concerns you have, so they can give you the best advice.

Second opinion

A second opinion is an opinion from a different doctor about your treatment. If you think you want a second opinion, talk to your specialist doctor or GP first. Tell them your concerns or ask them to explain anything you do not understand. This might help reassure you.

If you still want a second opinion, you can ask your specialist doctor or GP to arrange it. They are usually happy to do this. You may have to travel to another hospital to get a second opinion. Getting a second opinion could delay your treatment. Check with your doctor if this delay could be harmful to you.

If the doctor you see for the second opinion gives you the same advice, this can reassure you. Sometimes they give you other treatment options to think about.

We have more information about getting a second opinion on our website. Visit **macmillan.org.uk/second-opinion**

> **‘One positive of treatment – I had quite a large bald patch and I seem to be growing some “fuzzy” bits of hair which is down to the lack of testosterone.’**
>
> **John, diagnosed with advanced prostate cancer**

Hormonal therapy

Hormonal therapy is the main treatment for advanced prostate cancer. It can shrink the cancer, slow its growth and reduce symptoms.

Your doctor or nurse will talk to you about the type of hormonal therapy that is best for you. They will explain the different side effects and talk to you about your preferences (pages 56 to 59).

Prostate cancer needs the hormone testosterone to grow. Testosterone is mainly made by the testicles. A small amount is made by the adrenal glands, above each kidney. Hormonal therapies reduce the amount of testosterone in the body, or stop it reaching the prostate cancer cells.

Testosterone is important for:

- sex drive (libido)
- getting an erection
- facial and body hair
- muscle development and bone strength.

Having lower testosterone levels means that some of these things can be affected. We have more information on the side effects of hormonal therapies (pages 56 to 59).

Your doctor or nurse will check how well your hormonal therapy is working. They will ask about your symptoms, examine you and monitor your PSA level (page 23).

Measuring your PSA level is usually a good guide to how well treatment is working. If it goes up, they may talk to you about having a different treatment.

How hormonal therapy is given

Before you start hormonal therapy you will have some blood tests, including PSA level. Your doctor will also examine you and ask about your symptoms.

There are different types of hormonal therapy that may be used. Not all types of hormonal therapy are suitable for everyone. Your doctor or nurse will explain the drug that is most suitable for your situation. You may have treatment which involves having more than one type of treatment at a time.

You can have hormonal therapy as:

- injections
- implants
- a nasal spray
- tablets.

You might have a drug on its own or with another hormonal therapy.

Another way of lowering testosterone is to have an operation to remove the testicles. This is called an orchidectomy and is not commonly done (page 55).

You may have hormonal therapy with chemotherapy (pages 61 to 68) when you are first diagnosed with advanced prostate cancer. This may be more effective than hormonal therapy on its own. But there are more side effects to cope with. Your cancer doctor can tell you more about this.

Intermittent hormonal therapy

Instead of taking the drugs continuously, you may stop taking the drugs for a while and then start taking them again.

This is called intermittent hormonal therapy. It means you get a break from any side effects. This is not suitable for everyone. It should only be done following your doctor's advice.

Intermittent hormonal therapy may be helpful if certain side effects are difficult to cope with. Your doctor or nurse will explain the possible benefits and disadvantages. If your PSA level goes up or your symptoms get worse, your doctor will advise starting hormonal therapy again.

Hormonal therapy injections and implants

LHRH agonists

The pituitary gland in the brain makes a hormone called luteinising hormone (LH). This hormone tells the testicles to make testosterone. LHRH agonists affect this hormone and stop the testicles making testosterone. These are the most common type of hormonal therapy. You have them as an implant injection or an injection under the skin.

The commonly used LHRH agonists are:

- buserelin (Suprefact®)
- goserelin (Zoladex®, Novgos®)
- leuprorelin (Prostap®, Lutrate®)
- triptorelin (Decapeptyl®, Gonapeptyl Depot®).

A nurse or doctor at your GP practice or hospital can give you these drugs.

Tumour flare

The first time you have one of these drugs, it can cause an increase in testosterone for a short time. This can make any symptoms worse for a short time. This is sometimes called tumour flare. To prevent this, your doctor usually asks you to take an anti-androgen drug. You take it for a short time before and after starting the LHRH agonist.

GnRH antagonists

These drugs block messages from the brain to the testicles telling them to make testosterone. They work quicker than LHRH agonists and do not cause tumour flare. They are usually given if:

- cancer has spread to certain parts of the body, such as the spine
- cancer has spread to the spine and there is a risk it could press on the spinal cord.

Currently, degarelix (Firmagon®) is the only GnRH antagonist available. You have it as an injection under the skin (subcutaneously) of your tummy once a month. As well as hormonal side effects (pages 56 to 59), it commonly causes skin reactions.

Hormonal therapy as tablets

If the cancer starts growing during treatment with an injection or implant, your doctor may advise also taking an anti-androgen tablet.

Having the 2 drugs together can help to slow down the growth of the cancer and how quickly it spreads. You will not usually have combined hormonal therapy as your first treatment. This is because you may have more side effects if you are taking 2 drugs. Your doctor or specialist nurse can explain more about this.

You may have newer hormonal therapy drugs called abiraterone (Zytiga®) or enzalutamide (Xtandi®) along with an injection or implant.

Anti-androgen drugs

These drugs stop testosterone from reaching the cancer cells. You take them as tablets. They may be given:

- for 1 or 2 weeks before and after starting injections or implants, to stop symptoms getting temporarily worse (tumour flare)
- on their own
- with hormonal injections or implants (combined hormonal therapy).

An anti-androgen on its own may cause fewer sexual side effects and less bone thinning. But it may not control the cancer as well as other hormonal therapies.

Anti-androgen drugs include:

- bicalutamide (Casodex®)
- cyproterone acetate (Cyprostat®)
- flutamide.

Bicalutamide and flutamide can cause breast swelling or tenderness. As well as hormonal side effects, these drugs have different side effects of their own.

If you have been taking an anti-androgen drug for some months or years, and the cancer begins to grow, your doctor may stop the drug. This may make the cancer shrink for a while. Doctors call this a withdrawal response.

Enzalutamide and abiraterone

These newer drugs are usually used when other hormonal therapies are no longer helping to control the cancer. This is when the prostate cancer cells need much lower levels of testosterone to grow.

You may have these drugs earlier, when you are first diagnosed with advanced prostate cancer.

These newer hormonal therapy drugs may be given before you need chemotherapy (pages 61 to 68). This may happen if you have no symptoms or mild symptoms. If chemotherapy is no longer helping to control the cancer, they may be the first hormonal therapy drugs you have. You might have them with hormonal injections or implants, or on their own.

Abiraterone

You take abiraterone as tablets once a day, along with drugs called steroids. The steroids are given to lower the risk of some of the side effects. It may be given as a first treatment for advanced prostate, alongside other hormonal therapies.

If you have already had enzalutamide, you are unlikely to be offered abiraterone. This is because research suggests that men who have already had one of these drugs respond well to the other. Abiraterone is mainly given when other hormonal therapies are no longer controlling the cancer.

Side effects of abiraterone can include high blood pressure and changes to your heartbeat. Your doctor or specialist nurse can give you more information.

Enzalutamide

Enzalutamide may be given as a first treatment for advanced prostate, alongside other hormonal therapies. You take enzalutamide as a capsule once a day. If you have already had abiraterone, you are unlikely to be offered enzalutamide.

Side effects of enzalutamide can include high blood pressure and, less commonly, an increased risk of infection. Your doctor or specialist nurse can give you more information.

> **I used to talk to the cancer as well. I'd take abiraterone first thing in the morning, 4 large pills. I'd wake up and say, "Right then, this is what you're getting today – and there's going to be more."**
>
> **Paul, diagnosed with advanced prostate cancer**

Other hormonal treatments

Surgery to the testicles

Some people may have an operation to remove part or all of the testicles. This is called an orchidectomy. It is more common to use hormonal therapy drugs to reduce the amount of testosterone in the body. But it may be an option if you find it hard to have regular injections or to take tablets every day. It is as effective as other hormonal treatments. You can have the operation as a day patient (page 76).

The operation cannot be reversed, which may be upsetting. It causes most of the same side effects as other hormonal therapy drugs. It is important to talk with your doctor and nurse about this treatment.

Steroids

Sometimes steroid drugs such as prednisolone or dexamethasone are used to treat advanced prostate cancer. They work on the adrenal glands, to help reduce the amount of testosterone in the body.

They can be used on their own, but are usually given with abiraterone or chemotherapy (pages 61 to 68). You may have dexamethasone along with a hormonal injection or implant drug. Side effects may include:

- increased appetite
- weight gain
- difficulty sleeping
- irritability.

Oestrogen

Treatment with the hormone oestrogen may help to reduce testosterone levels. It is sometimes used when other hormonal therapies are no longer working. The most commonly used drug is diethylstilbestrol (Stilboestrol®). You take it as a tablet.

The side effects are similar to other hormonal therapies. It can also increase the risk of getting a blood clot, so it may not be suitable for some people.

Side effects

Hormonal therapies have similar side effects because they all reduce the amount of testosterone in the body. But individual drugs do have different side effects. It is important to discuss these with your doctor or nurse before you start treatment, so you know what to expect.

Erection difficulties

Most hormonal therapies cause loss of sexual desire and erection difficulties (called erectile dysfunction, or ED).

LHRH agonists usually completely stop erections during treatment. Anti-androgens stop erections in most people. If you have ED, there are drugs and treatments that may help. Your doctor or nurse will talk to you about this.

Hot flushes and sweats

These may happen less often as your body adjusts to treatment. Wearing layers of light clothing (such as cotton) can help. This means you can easily take off or put back on clothes as needed. Having less alcohol, nicotine and hot drinks that contain caffeine can also help. If your hot flushes are causing you difficulty, your doctor may give you a drug to help.

Tiredness (fatigue)

Tiredness is a common side effect. It can be made worse by hot flushes, which may make sleeping difficult. Pace yourself so you have more energy to do the things you want. Regular physical activity, such as walking, can help give you more energy.

Ask your team for advice on the type of exercise that is suitable for your situation. If tiredness makes you feel sleepy, do not drive or operate machinery.

We have more information in our booklet **Coping with fatigue (tiredness)** – page 130.

Breast swelling or tenderness

This is more common if you have flutamide or and bicalutamide over a longer period. Some people have low-dose radiotherapy to their chest before treatment to prevent breast swelling.

If you are taking bicalutamide, another option is to take a hormonal drug called tamoxifen to reduce breast swelling.

Weight gain and loss of muscle strength

You may gain weight (often around the tummy) with hormonal therapy. Try to eat a healthy, balanced diet. Regular physical activity such as short walks, can help keep your weight stable. It also helps look after your muscles. Ask your doctor or nurse for advice.

You can find more information in our booklets **Physical activity and cancer** and **Healthy eating and cancer** (page 130).

> ‘Going on hormones, I ended up sleeping all the time. It knocks all the stuffing out of you. Sometimes it was quite a struggle to stay awake for the day.’

Paul, diagnosed with advanced prostate cancer

Bone thinning

Hormonal therapy can cause bone thinning (osteoporosis). This can sometimes lead to tiny cracks in the bone (fractures). The risk increases if you are taking hormonal therapy for long periods. If you are starting long-term hormonal treatment, your doctors may arrange for you to have a DEXA (dual-energy x-ray absorptiometry) scan. This allows them to check your bones for any areas of weakness.

Weight-bearing exercises, such as walking, can help look after your bone health. Eating a healthy balanced diet can also help. We have more information in our **Bone health** booklet (page 130).

If your bones are thinning, your doctor may advise you to take calcium and vitamin D tablets. They may also ask you to take bone-strengthening drugs called bisphosphonates or a drug called denosumab (Prolia®).

Mood changes

You may have mood changes and feel emotional or anxious. This can be a side effect of hormonal therapy, but it can also be because you are coping with advanced cancer. Tell your cancer doctor or nurse if these feelings are difficult to cope with. They can support you or refer you to a doctor or counsellor who specialises in emotional support. They may also prescribe drugs to help if needed.

We have more information in our booklet **Talking about cancer** (page 130).

Chemotherapy

Chemotherapy uses anti-cancer (cytotoxic) drugs to destroy cancer cells. It is given with hormonal therapy when you are first diagnosed with advanced prostate cancer. It may also be used to treat advanced prostate cancer that is no longer being controlled by hormonal therapy (pages 47 to 59).

The aim of chemotherapy for advanced prostate cancer is to shrink the cancer and slow its growth. This will help to relieve symptoms and improve quality of life.

The most commonly used chemotherapy drug to treat prostate cancer is docetaxel (Taxotere®). Other drugs that may be used are:

- cabazitaxel (Jevtana®)
- mitoxantrone.

How chemotherapy is given

The chemotherapy drugs are given into a vein (intravenously). The drugs get into the blood and can reach cancer cells all over the body.

You can have chemotherapy drugs through:

- a cannula – a short, thin tube the nurse puts into a vein in your arm or hand
- a central line – a fine tube that goes under the skin of your chest and into a vein close by
- a PICC line – a fine tube that is put into a vein in your arm and goes up into a vein in your chest.

You usually have several sessions of treatment. Each session is followed by a rest period of a few weeks. Chemotherapy and the rest period make up a cycle of treatment. Your cancer doctor will explain how many cycles you need to treat the cancer.

We have more information about chemotherapy in our booklet **Understanding chemotherapy** (page 130).

Side effects

The side effects you get will depend on the chemotherapy drugs you are having. Different drugs cause different side effects. You may get some of the side effects we mention here, but you are unlikely to get all of them.

Some side effects are mild and can be treated easily. Your doctor, nurse or pharmacist may give you drugs to help control them.

Most side effects stop or gradually get better when chemotherapy is over.

Risk of infection

This treatment can reduce the number of white blood cells in your blood. These cells fight infection. If the number of white blood cells is low, you are more likely to get an infection. A low white blood cell count is called neutropenia.

An infection can be very serious when the number of white blood cells is low. It is important to get any infection treated as soon as possible. Contact the hospital straight away on the 24-hour contact number you have if:

- your temperature goes over 37.5°C (99.5°F)
- you suddenly feel unwell, even with a normal temperature
- you have symptoms of an infection
- your temperature goes below 36°C (96.8°F).

Symptoms of an infection include:

- feeling shivery and shaking
- a sore throat
- a cough
- breathlessness
- diarrhoea
- needing to pass urine (pee) a lot, or discomfort when you pass urine.

It is important to follow any specific advice your cancer treatment team gives you.

The number of white blood cells will usually return to normal before your next treatment. You will have a blood test before having more treatment. If your white blood cell count is low, your doctor may delay your treatment for a short time, until your cell count increases.

Bruising and bleeding

This treatment can reduce the number of platelets in your blood. Platelets are cells that help the blood to clot.

If the number of platelets is low, you may bruise or bleed easily. You may have:

- nosebleeds
- bleeding gums
- heavy periods
- blood in your urine (pee) or stools (poo)
- tiny red or purple spots on the skin that may look like a rash.

Tell your doctor if you have any unexplained bruising or bleeding. You may need a drip to give you extra platelets. This is called a platelet transfusion.

Anaemia (low number of red blood cells)

This treatment can reduce the number of red blood cells in your blood. Red blood cells carry oxygen around the body. If the number of red blood cells is low, this is called anaemia. You may have symptoms such as:

- pale skin
- lack of energy
- feeling breathless
- feeling dizzy and light-headed.

Tell your doctor or nurse if you have these symptoms.

If you are very anaemic, you may need a drip to give you extra red blood cells. This is called a blood transfusion.

Feeling sick

Your doctor will give you anti-sickness drugs to help prevent or control sickness during your treatment. Take the drugs exactly as your nurse or pharmacist tells you. It is easier to prevent sickness than to treat it after it has started.

If you feel sick, take small sips of fluids often and eat small amounts regularly. It is important to drink enough fluids. If you continue to feel sick, or are sick (vomit) more than once in 24 hours, contact the hospital as soon as possible.

They will give you advice. Your doctor or nurse may change the anti-sickness drug to one that works better for you.

Loss of appetite

This treatment can affect your appetite.

Don’t worry if you do not eat much for a day or two. But if your appetite does not come back after a few days, or if you are losing weight, tell your nurse or dietitian. They can give you advice. They may give you food or drink supplements. Or they may suggest changes to your diet or eating habits to help.

We have more information in our booklet **Eating problems and cancer** (page 130).

Sore mouth and throat

This treatment may cause a sore mouth and throat. You may also get mouth ulcers. This can make you more likely to get a mouth or throat infection. Use a soft toothbrush to clean your teeth or dentures in the morning, at night and after meals.

If your mouth or throat is sore:

- tell your nurse or doctor – they can give you a mouthwash or medicines to help
- try to drink plenty of fluids
- avoid alcohol, tobacco and foods that irritate your mouth and throat.

Sucking ice chips may sometimes help relieve mouth or throat pain. But if you are having radiotherapy to the head or neck, do not suck on ice. It can cause damage.

Hair loss

Your hair will get thinner. Or you may lose all the hair from your head. You may also lose your eyelashes and eyebrows, as well as other body hair. Hair loss usually starts after your first or second treatment.

Your nurse can talk to you about ways to cope with hair loss. There are ways to cover up hair loss if you want to. Your scalp may be sensitive. It is important to cover your head to protect your scalp when you are out in the sun.

Hair loss is almost always temporary. Your hair will usually grow back after treatment finishes. We have more information in our booklet **Coping with hair loss** (page 130).

Feeling tired

Feeling tired is a common side effect. It is often worse towards the end of treatment and for some weeks after it has finished. Try to pace yourself and plan your day so you have time to rest. Gentle exercise, like short walks, can give you more energy. If you feel sleepy, do not drive or operate machinery.

We have more information in our booklet **Coping with fatigue (tiredness)** – page 130.

> **‘The first 6 rounds of treatment I experienced no side effects. But the next 2 knocked me sideways and left me suffering from diarrhoea and tiredness. Other than that, I felt fine.’**
>
> **Colin, diagnosed with advanced prostate cancer**

Diarrhoea

This treatment may cause diarrhoea. Diarrhoea means passing more stools (poo) than is usual for you, or having watery or loose stools. If you have a stoma, it will be more active than usual.

If you have diarrhoea:

- try to drink at least 2 litres (3 1/2 pints) of fluids each day
- avoid alcohol, caffeine, milk products, high-fat foods and high-fibre foods
- contact the hospital for advice.

Numb or tingling hands or feet (peripheral neuropathy)

This treatment may affect the nerves, which can cause numb, tingling or painful hands or feet. You may find it hard to fasten buttons or do other fiddly tasks.

Tell your doctor if you have these symptoms. They sometimes need to lower the dose of the drug. The symptoms usually improve slowly after treatment finishes. But for some people they may never go away. Talk to your doctor if you are worried about this.

Radiotherapy

Radiotherapy uses high-energy rays to treat cancer. It destroys cancer cells in the area where the radiotherapy is given. Doctors use it in different situations to treat advanced prostate cancer.

Radiotherapy for advanced prostate cancer is most often used to shrink cancer that has spread to the bones.

It can strengthen the bone and reduce pain. This helps to keep you as active as possible without being in pain. Sometimes treatment to the bones may also help you live longer.

Radiotherapy can also help to:

- relieve pain if the cancer is in a lymph node (page 10) or pressing on the back passage (rectum)
- control bleeding in the urine (pee).

Radiotherapy to relieve your symptoms is called palliative radiotherapy.

How radiotherapy is given

Radiotherapy to treat advanced prostate cancer can be given in 2 ways:

- External beam radiotherapy is given from outside the body (externally) from a radiotherapy machine.
- Radioisotope liquid is injected into a vein.

Your pain may get better within a few days of treatment, or it may take a few weeks. It may be up to 6 weeks before you feel the full benefit. Sometimes, the pain may get worse before it gets better.

You will need to keep taking painkillers during this time. Tell your cancer doctor or nurse if the pain gets worse, so they can increase your painkillers. When the treatment has worked, they can reduce them.

External beam radiotherapy for advanced prostate cancer

You can have external beam radiotherapy as an outpatient in the radiotherapy department. Some people may need to stay in hospital while they have it. Radiotherapy is given using a machine that is like a big x-ray machine. This is called a linear accelerator (often called a LINAC).

You may have external beam radiotherapy as a single treatment or as a few sessions over a few weeks.

At the start of the session, the radiographer will make sure you are in the correct position on the couch and that you are comfortable. Radiotherapy is not painful. But you must lie still during the treatment. You may want to take your painkillers before you have it.

When everything is ready, the radiographer leaves the room so you can have the radiotherapy. The treatment only takes a few minutes. You can talk to the radiographers through an intercom or signal to them during the treatment. They can see and hear you from the next room.

Your cancer doctor, nurse or radiographer will explain your treatment and its possible side effects. They can give you advice on what you can do to manage any side effects. They can also help answer any questions you may have.

Side effects

The side effects of palliative radiotherapy are usually mild. They will depend on the area of the body that is being treated.

Feeling very tired is a common side effect. This should gradually improve a few weeks after treatment finishes. Try to pace yourself and plan your day so you have time to rest. Gentle exercise, like short walks, can give you more energy.

You may feel sick if the area treated is close to your tummy, for example the ribs or spine. Your doctor can give you anti-sickness drugs to help prevent or control sickness.

If you only have 1 or 2 treatment sessions, you may have flu-like symptoms for a few days afterwards.

Always tell your nurse or radiographer about any side effects. There are usually ways to treat or manage them.

We have more information in our booklet **Coping with fatigue (tiredness)** – page 130.

Malignant spinal cord compression

If a tumour is close to or pressing on the spinal cord, it is called malignant spinal cord compression (MSCC). Doctors can treat this with a short course of external radiotherapy to the spine. You may have a single treatment or up to 2 weeks of radiotherapy.

MSCC causes symptoms, such as:

- a new pain in your neck or back
- numbness or pins and needles in your feet or hands
- difficulty walking.

Spinal cord compression is not common, but it needs to be treated quickly to stop permanent damage to the nerves. Always tell your doctor straight away if you have any of these symptoms.

We have more information about MSCC in our leaflet **Malignant spinal cord compression** (page 130).

Radioisotope therapy

Radioisotope therapy can be used to treat prostate cancer that has spread to the bones.

This treatment uses radioactive substances called radioisotopes. Cancer cells absorb radioisotopes more than normal cells do. This means they get a higher dose of radiation to destroy them. All the bones affected by cancer will be treated. It can be very helpful if the cancer is in different areas of bone.

You may be given a radioisotope if hormonal therapy (pages 47 to 59) is no longer helping to control prostate cancer that has spread to the bone.

The radioisotope used is called radium-223 (Xofigo®). It is usually given once a month for 6 treatments.

Before radioisotope therapy, you have a blood test to make sure your blood cells are at a normal level. This is because radioisotopes can reduce the number of blood cells.

The radiographer will give you the radioisotope as an injection into a vein in your arm. This only takes a few minutes. When they are finished, they cover the area with a small plaster.

After the injection, you will have some radioisotopes in your stools (poo), urine and blood. Because of this, there are certain precautions you need to take when you go to the toilet.

This is to protect yourself and others from being exposed to the radiation. You only need to do this for 1 week. For example, they will ask you to sit down to use the toilet rather than use a urinal. It is still safe for you to be with other people, including children. The hospital staff will explain more about this.

You have the treatment as an outpatient in the radiotherapy department and go home on the same day. The hospital will give you information about this treatment.

Side effects

The side effects of radioisotope therapy are usually mild. You may have some diarrhoea or feel slightly sick. Your doctor can give you drugs to control these effects if needed.

The treatment can sometimes reduce the number of your blood cells for a short time. This is not usually a problem. But if you notice any unusual bruising or bleeding, contact the hospital straight away.

Surgery

You may be offered surgery for advanced prostate cancer. The aim of the surgery is to help with symptoms rather than to treat the cancer.

Before the operation, the surgeon (a urologist) will explain what will happen. They will also talk to you about any possible side effects.

Subcapsular orchidectomy

This is an operation to remove part of the testicles. The aim is to reduce the level of the male hormone testosterone in the body. It is not commonly used because hormonal therapy treatment is usually effective at reducing the testosterone levels.

We have more information about hormonal therapies (pages 47 to 59).

Transurethral resection of the prostate (TURP)

Your doctor may offer you a transurethral resection of the prostate (TURP) if the cancer is blocking the urethra. This is the tube that drains urine from the bladder. The aim of the surgery is to remove the blockage, which can help with problems passing urine (peeing) and improve your symptoms.

You may have a TURP before radiotherapy (pages 70 to 75). Radiotherapy can make passing urine more difficult during and after treatment.

A TURP can be done under a general anaesthetic. Or you may have a spinal anaesthetic (epidural). An epidural numbs the lower part of your body for a period of time. It is an injection of anaesthetic into the spine. You are awake, but you will not feel anything.

During surgery, the surgeon passes thin tube through the urethra and into the prostate. This tube contains a cutting instrument and a tiny camera. The cutting instrument is used to shave off the inner area of the prostate and unblock the urethra.

A TURP can also be done using a special laser. This is only done in some specialist treatment centres. Your doctor will advise you if this is suitable for you, and where the treatment is available.

After your TURP

You will be encouraged to start moving around as soon as you can after your operation. This can help lower the risk of complications.

After a TURP, you will usually have a drip (intravenous infusion) into a vein in your arm. This will stay in for a few hours after your operation, until you are eating and drinking again. You can usually go home after 3 or 4 days.

Catheter

You will have a tube (catheter) to drain urine (pee) from the bladder into a bag. After a TURP, your urine will have blood in it for a while. To stop blood clots blocking the catheter, fluid is passed into the bladder and drained out through the catheter. This is called bladder irrigation. The blood will slowly clear from your urine, and then the catheter can be taken out.

You may find it difficult to pass urine without the catheter at first, but this will improve. You may have urinary incontinence after a TURP, but this usually improves within a few weeks.

You may need to keep the catheter in for a while after you go home. This is because swelling caused by the surgery may make it difficult for you to pass urine. The nurse will show you how to look after your catheter before you leave the hospital. They can also organise for a district nurse to visit you at home to help with any problems. When the swelling goes down, the catheter can be removed.

If you go home with a catheter, you may have bladder spasms. These are caused by the catheter irritating your bladder. The spasms can cause urine to bypass your catheter, so you may leak urine at times. You may find them uncomfortable. These spasms are normal, but if they last a long time and are frequent, tell your doctor or nurse.

Pain

You may have pain and discomfort for a few days after your operation. You will be given painkillers to help with this. If the painkillers are not helping, talk to your doctor or nurse. They can give you another type of painkiller. We have more information about pain in our booklet **Managing cancer pain** (page 130).

Ejaculating into the bladder

Ejaculating into the bladder is called retrograde ejaculation. It is caused by damage to the nerves or muscles that surround the neck of your bladder. The neck of your bladder is where the urethra joins on to the bladder. It means that during ejaculation, semen goes backwards into the bladder instead of through the urethra in the normal way. After an ejaculation, your urine may look cloudy. This is because there is semen in the bladder, but this is harmless.

Erection problems

You may have problems getting an erection after the TURP. This is called erectile dysfunction (ED). It might depend on whether you had problems getting an erection before the operation, or if you were on hormone therapy. Your surgeon can tell you more about your risk of erection problems.

Difficulties passing urine

Sometimes, a TURP can cause some long-term difficulties with passing urine.

Percutaneous nephrostomy and JJ stent

The tubes that connect the kidneys to the bladder (ureters) may get blocked by the prostate cancer. This will make it difficult to pass urine. If this happens, you may be offered one of the following types of surgery:

- Percutaneous nephrostomy – the doctor puts a tube into the kidney. The tube goes into a bag that sits outside on the skin. Urine can then drain into the bag.
- JJ stent – the doctor puts a fine tube into the ureter. The tube is called a JJ stent. This opens up the ureter, so urine can flow through it.

Your doctor or specialist nurse can give you more information about these types of surgery.

Strengthening a weakened bone

Advanced prostate cancer that has spread to the bones may cause problems that need treating. If there is a risk of a bone breaking, your doctor may advise surgery to strengthen or repair the bone.

Going home after surgery

If you think you might have difficulties coping at home after your surgery, tell your nurse or social worker when you go into hospital. They can arrange help for when you go home. Social workers can offer practical advice and valuable support to you and your family. If you would like to talk to a social worker, ask your nurse or doctor to arrange this for you.

Before you leave hospital, you will be given an appointment at an outpatient clinic for your post-surgery check-up. This is a good time to talk about any problems you may have.

Clinical trials

Clinical trials are medical research studies involving people. Doctors may use cancer clinical trials to:

- test new treatments to see if they work better than current treatments
- find which treatments have fewer side effects
- find new ways to combine treatments to see if they work better
- test new cancer drugs to find out more about them and their side effects
- improve the way treatments are given to try to reduce side effects.

Results from clinical trials can improve cancer treatments and help people live longer. Trials can also look at improving things like diagnosis and symptom management.

Taking part in a trial

Your cancer doctor or specialist nurse may talk to you about taking part in a clinical trial. Or you could ask them if there are any trials suitable for you.

Usually, cancer clinical trials happen in several hospitals around the country. You may have to travel to take part in a trial.

A research nurse or doctor will give you information about the trial. It is important to understand what is involved before you agree (consent) to take part. You can ask the research nurse or doctor any questions you have.

They will also explain the possible benefits and any possible risks of the trial. Clinical trials are designed to be as safe as possible. The researchers will monitor you closely during and after the trial.

If you decide not to take part in a trial, your cancer doctor and specialist nurse will respect your decision. You do not have to give a reason for not taking part. Your decision will not change your care. Your cancer doctor will give you the standard treatment for the type and stage of cancer you have.

We have more information about cancer clinical trials at **macmillan.org.uk/clinical-trials**

Giving blood and tissue samples

During your diagnosis and treatment doctors often take blood samples. They may also take a small piece of tissue or a sample of cells. These tissue samples are called biopsies. The samples can be looked at under a microscope. Your cancer doctor may ask your permission to store and use these blood or tissue samples for cancer research. This will only happen after they have done all the tests you need.

Your samples can only be stored for research if you give your consent. Your cancer doctor can answer any questions you have. Your name is removed from the samples before they are stored. This means you cannot be identified. The samples may be used to:

- find out more about the causes of certain cancers
- develop new cancer drugs or treatments.

This type of research takes a long time. The results may not be available for many years.

COPING WITH ADVANCED PROSTATE CANCER

Managing symptoms

Advanced prostate cancer may cause symptoms that are difficult to cope with. But there are different ways to manage or control them. Treatments for the cancer can also improve symptoms. But they sometimes take a few weeks to work.

Different members of your cancer team can support you. You may see a doctor or nurse who specialises in pain and symptom control. They are sometimes called palliative care specialists.

A physiotherapist can advise you if you have problems walking. They can plan an exercise programme and help you build your muscle strength. Occupational therapists can also help with equipment that makes it easier and safer to manage at home.

Tiredness

You may feel extremely tired (fatigued). This can be because of the cancer and treatment side effects. There are things you can do to help manage tiredness:

- Pace your everyday activities and save energy for things you want to do.
- Accept offers of help from others, or ask for help when you need it.
- Try to be more physically active to improve your energy levels – for example, by going for regular short walks. We have more information in our booklet **Physical activity and cancer** (page 130).
- Eat healthily to give you more energy and help you feel better. We have more information in our booklet **Healthy eating and cancer** (page 130).
- Try some complementary therapies such as relaxation techniques, which may help you to feel less anxious and tired. We have more information in our booklet **Cancer and complementary therapies** (page 130).

If you are having problems getting around, ask to see a physiotherapist or occupational therapist. Using a walking aid may allow you to move more easily.

Tell your doctor or nurse if you are very tired. They can test your blood to make sure you do not have anaemia (a low level of red blood cells). This can make you feel tired and sometimes breathless. You may need a blood transfusion to improve this.

We have more information in our booklet **Coping with fatigue (tiredness)** – page 130.

Pain

Always tell your doctor or nurse if you have pain. There are different painkillers that work in different ways. You can take painkillers:

- by mouth
- as injections under the skin
- as patches on the skin.

If pain is a problem, try to take your painkillers regularly. Even if you are not in pain when the next dose is due, taking regular painkillers can stop pain coming back. If your painkillers are not working well, tell your doctor. They can increase the dose or change the painkiller to one that works better for you.

There are special NHS pain clinics run by doctors and nurses who are experts in treating pain. If there are problems controlling your pain, you can ask your doctor to refer you to a clinic.

Treating bone pain

The most common place for advanced prostate cancer to spread to is the bones. There are different ways bone pain can be controlled. You may be given:

- drugs called non-steroidal anti-inflammatory drugs (NSAIDs)
- bone-strengthening drugs called bisphosphonates
- 1 or 2 sessions of radiotherapy.

Radiotherapy is effective at helping with bone pain but can take a few weeks to work (pages 70 to 75). Take your painkillers regularly until the radiotherapy works.

Bisphosphonates

Drugs such as zoledronic acid (Zometa®) help to:

- strengthen bones
- lower the risk of fractures
- reduce bone pain.

You can have bisphosphonates as a drip (infusion) into a vein. You have this in the outpatient department every 3 to 4 weeks. Bisphosphonates can also reduce high levels of calcium in the blood (hypercalcaemia) caused by the cancer in the bones.

Denosumab

Denosumab (Xgeva®, Prolia®) is a type of targeted therapy drug that can also be used to help strengthen bones. It is given as an injection just under the skin (subcutaneously) every 4 weeks. Your doctor or nurse can give you more information.

Treating bone problems

For some people, secondary cancer in the bones may cause problems that need treatment. There are ways of managing these. We have more information in our booklet **Understanding secondary cancer in the bone** (page 130).

Hypercalcaemia

Secondary cancer in the bones may cause calcium to be released from the bones into the blood. This is not common in prostate cancer.

If you have high levels of calcium in the blood, it can make you:

- feel sick
- thirsty
- drowsy
- constipated.

Tell your doctor or nurse if you have these symptoms. It is important hypercalcaemia is diagnosed and treated quickly.

Your nurse or doctor will give you a drip (infusion) of fluids. This is to help to flush out the extra calcium from your body. They also give you bisphosphonates as a drip to lower the calcium levels. Your symptoms should go away within a few days.

Strengthening a weakened bone

If there is a risk of a bone breaking, your doctor may advise surgery to strengthen or repair the bone. This is done under a general anaesthetic.

The surgeon puts a metal rod down the middle of the bone, or fixes a metal plate on the outside of the bone. This holds the bone so that it will not break. The rods or plates stay in permanently. This is mainly used to treat the long bones in the legs.

You may have surgery to the spine. Or you may have a hip joint replaced that has been damaged by the cancer.

You may need to stay in hospital for a week or longer after surgery so you can fully recover. You can get up and start walking a few days after the operation.

You may have radiotherapy before or after surgery. This can help repair the bone, or try to destroy any cancer cells.

Malignant spinal cord compression

Malignant spinal cord compression (MSCC) happens when cancer cells grow in, or near to, the spine and press on the spinal cord and nerves.

Symptoms of MSCC include:

- back or neck pain – the first symptom is often severe pain that comes on slowly
- numbness or pins and needles in your toes, fingers or buttocks
- feeling unsteady on your feet
- bladder or bowel problems.

If you notice any of these symptoms, contact your cancer doctor, nurse or GP straight away so they can do some tests.

The earlier treatment starts, the more likely it is to be effective. Steroids, radiotherapy and surgery may all be used, depending on your situation. Your doctor will talk to you about any possible risks first. We have information about MSCC in our leaflet **Malignant spinal cord compression** (page 130). We also have more information on our website. Visit **macmillan.org.uk/malignant-spinal-cord-compression**

Bladder or bowel problems

If you have bladder problems, such as needing to pass urine (pee) urgently or leakage, there is help available. Your nurse can advise you, or put you in touch with a continence service. There are different pads you can use and treatments that may help. The Bladder and Bowel Community has useful information (page 135).

If you have pelvic radiotherapy you may develop bowel problems, such as diarrhoea, much later. There are different ways to manage the late effects of pelvic radiotherapy. Your doctor can give you drugs to help control diarrhoea.

You may also have constipation. This can be caused by:

- certain painkillers
- being less active than usual
- not eating enough high-fibre foods.

There are things you can do to help, including:

- having more fibre in your diet
- drinking plenty of fluids
- going for regular short walks.

Your doctor may need to give you medicine (a laxative) to make your bowels work.

Macmillan toilet card

We have a card you can order if you are having bowel or bladder problems. If you need to use a toilet urgently, you can show this card in places such as shops, offices, cafes and pubs. You can use it during or after treatment.

We hope it allows you to get access to a toilet without any awkward questions. But we cannot guarantee that it will work everywhere.

We have more information in our booklets **Managing the bladder late effects of pelvic radiotherapy** and **Managing the bowel late effects of pelvic radiotherapy** (page 130).

Eating difficulties

If you have eating difficulties or are worried about losing weight or gaining weight, there is lots of information to help you. You can ask your nurse or a dietitian for advice.

If you have lost weight, food supplements can provide more protein and energy, and help improve your weight. Your dietitian can give you advice on this. If your appetite is not good, try eating small meals often and sipping nutritional drinks. You can get some of these on prescription.

Weight gain can be a side effect of hormonal therapy. Eating healthily and cutting down on foods that are high in fat or sugar can help manage your weight. Try to only eat as much as you need. Combine this with regular exercise, such as short walks.

We have more information in our booklet **Eating problems and cancer** (page 130).

Complementary therapies

You may find that complementary therapies, such as relaxation, gentle massage or aromatherapy, help you to feel better and more in control. They may reduce symptoms of anxiety or help with pain.

Tell your doctor or nurse if you plan to use any complementary therapies. They can advise you if a complementary therapy is suitable for your situation. It is also important to use a qualified therapist and tell them about your diagnosis.

We have more information in our booklet **Cancer and complementary therapies** (page 130).

Sex

Treatments for prostate cancer can affect your sex life and relationships. Symptoms of the cancer, or side effects of treatment, can make it difficult to have sex. You may feel too tired for sex or have discomfort that makes it difficult. Feelings such as anxiety or sadness can also affect how you feel about sex.

If cancer and its treatments affect your sex life, it can feel very difficult to cope with. You do not need to be in a relationship to feel this. It can also affect how you feel and think about your body (body image). You may feel less sexually attractive. If you are having issues with your body image, ask your doctor or nurse for advice.

Being more physically active, eating healthily and managing your weight may help to improve body image concerns. Ask your doctor or nurse for advice.

We have more information in our booklets **Healthy eating and cancer**, **Managing weight gain after cancer treatment** and **Body image and cancer** (page 130).

Sexual difficulties

Prostate cancer treatments can have a direct effect on your sex life. The difficulties you have will depend on the treatment you have. You may already have sexual difficulties because of:

- previous prostate cancer treatments
- other medical conditions
- your age.

Your doctor or nurse will explain the effects of your treatment on your sex life. This may be an important factor in making your treatment decisions. We have more information in our booklet **Cancer and your sex life** (page 130).

Effects of treatments may cause:

- a reduced or loss of interest in sex
- difficulties getting or keeping an erection (erectile dysfunction, or ED)
- difficulties having an orgasm or ejaculating
- the penis and testicles to get smaller, if you are taking hormonal therapy for a long time.

Talking about sex

You may find it difficult to talk about sex with your doctor or nurse. But it is important to have your questions answered and to get the help you need. Your doctor, specialist nurse or GP should make you feel comfortable during conversations about sex. They are used to talking about these issues and they can give you advice and answer your questions.

You may want to think about whether there is someone in your healthcare team you feel more comfortable talking to. To help you feel prepared, plan what you want to say in advance and write down your questions. If you have a partner, you may want them with you at these discussions. Or you may prefer to talk confidentially with your doctor or nurse. If you need more specialist advice your doctor or nurse can refer you to an ED clinic or a sex therapist.

If you find it difficult talking to your doctor or nurse or getting information, there is other support available. You can talk to in confidence to a cancer information nurse specialist on our Macmillan Support Line or through email (page 132).

Prostate Cancer UK also has a helpline where you can talk or chat online to a specialist prostate nurse (page 135).

If you identify as LGBT+

There may be times when it helps your healthcare team to know how you identify your gender or sexual orientation. It may help you feel better supported. They can give the right information and support to you, and your partner if you have one.

The impact of cancer and cancer treatment are often the same whatever your sexual orientation or gender. But you may have some specific questions about how these will affect your sexual well-being.

Prostate Cancer UK has specific information for gay and bisexual men and trans (transgender) women – page 135.

If your healthcare team cannot help, they can refer you to a sex therapist or another specialist who can. If you want to talk things through, call the LGBT Foundation for confidential advice and support (page 142).

Managing sexual difficulties

Loss of sex drive and erection difficulties are common side effects of hormonal therapy (pages 47 to 59).

There are no treatments that increase your sex drive (libido) while you are having hormonal therapy. When you stop taking it, many side effects gradually go away. It is sometimes possible to have breaks in hormonal therapy (called intermittent hormonal therapy). This may also help with these side effects.

Treatments for erectile dysfunction (ED) may help you get an erection. But they cannot increase your sex drive. Your doctor or nurse will give you information about this. Many treatments work by increasing the blood supply to the penis.

If you need support coping with sexual difficulties, your nurse or doctor can give you information. They can also refer you to specialist support services.

Tablets

This is the most common treatment for ED. These tablets work by improving the blood supply to the penis. You take them before you have sex. You need to have sexual stimulation to get an erection before taking the tablets. If you have heart problems or are taking certain drugs, these may not be recommended for you. Your doctor or nurse can explain more about this and their possible side effects.

Tablets to treat ED include:

- sildenafil (Viagra®) – you take it about 60 minutes before sex and it should be prescribed by your GP
- vardenafil (Levitra®) – this is like sildenafil and you take it 25 to 60 minutes before sex
- tadalafil (Cialis®) – you take it at least 30 minutes before sex
- avanafil (Spedra®) – you take it 15 to 30 minutes before sex.

Urethral stick

You use a small applicator to insert a drug called alprostadil (MUSE®) directly into the urethra (page 8). The drug reduces blood flow out of the penis, causing an erection in 5 to 20 minutes. A healthcare professional will give you the first dose and teach you how to do this yourself.

Pellets or creams

Pellets or creams can be put into the opening of the penis with an applicator. The cream or pellet is absorbed into the penis and produces an erection.

Pumps

Vacuum pumps can also be used to produce an erection. They are also called vacuum erection devices (VEDs).

The pump is a hollow tube that you put your penis into. It makes the penis fill with blood by creating a vacuum. You put a stretchy ring around the base of the penis to hold the erection.

You should not wear it for more than 30 minutes.

Relationships

If you have a partner

If you have a partner, talking openly with them can help you feel closer. It can also help you make changes to your sex life together. Talking about things can help you avoid misunderstandings and find ways to cope with problems.

We have more information in our booklet **Cancer and relationships: Support for partners, families and friends** (page 130)

There are different ways you can show your partner you care about them. This can include spending time together and showing affection through touching, holding hands or putting an arm around them. You may also find new ways to share sexual pleasure.

Talking to a counsellor or sex therapist may help you and your partner adapt to changes in your sex life. You can ask your partner to come to appointments with you. This will help them understand the issues you are dealing with.

If you are single

If you are not in a relationship, it is natural to worry about meeting a new partner or about your sex life. You may need some time to come to terms with what has happened. It may help to talk to a counsellor or sex therapist. The College of Sexual and Relationship Therapists (COSRT) has a list of nationwide counsellors and therapists who can offer advice and support (page 136).

YOUR FEELINGS AND RELATIONSHIPS

Your feelings

It is common to have many different emotions when you are told you have cancer. These can be difficult to cope with. We talk about some common feelings here. Partners, family and friends may also have some of the same feelings.

There are lots of different reactions to cancer. You might not have any of the emotions we talk about here. There is no right or wrong way to feel. You will cope with things in your own way.

Talking to family, friends or other people affected by cancer, may help. Or you may get support from your healthcare team.

> **It lifted a weight off me. If we had a mawry, we could call our Macmillan nurse. And I didn’t realise that they’re there just as much for your partner and the people around you.**
>
> **Paul, diagnosed with advanced prostate cancer**

Shock and denial

You may find it hard to believe that you have cancer when you are first diagnosed. It is common to feel shocked and numb. You may not be able to understand all the information you are given. You may find that you keep asking the same questions. At first, it can be hard to talk about the cancer.

Or you might find it hard to think or talk about anything else. Both reactions are normal. Your mind is trying to process what is happening. These feelings usually get easier over time.

Fear and anxiety

You may be anxious or frightened about whether treatments will work and what will happen in the future. This can be one of the hardest things to cope with. It can help to try to focus on things you can control.

You may want to find out more about the cancer, your treatment options, and how to manage any side effects. It can also help to talk about your feelings. Try to keep doing the things that are important to you and that you enjoy.

Sadness and depression

You may feel sad if you have to change your plans because of the cancer, or if your future feels uncertain. Feeling sad is a natural reaction to changes or loss. This feeling may come and go during and after your treatment. For most people, these periods of sadness get better. But for some people, the sadness may continue or get worse. If you think the sadness may be turning into depression, there are things you can do to help.

Avoidance

You may cope by trying not to find out much about the cancer. Or by not talking about it. If you feel like this, tell people that you do not want to talk about it right now. You can also tell your cancer doctor if there are things you do not want to know or talk about yet.

Sometimes, it may be hard to accept that you have cancer. This can stop you making decisions about treatment. If this happens, it is very important to get help from your healthcare team.

You may feel that your family or friends are avoiding you or avoiding talking about the cancer. This is usually because they are also finding it difficult to cope. They may need support too. Try to tell them how this makes you feel. It may help you, and your family and friends, to talk openly about how you are feeling.

Anger

You may feel angry about your diagnosis. You may also resent other people for being well. These are normal reactions. They are more likely when you feel frightened, stressed or unwell. You may get angry with your family, friends or partner. Tell them you are angry at your illness and not at them.

Finding ways to relax can help with anger. This can include talking about or writing down how you feel, doing gentle exercise, having relaxation therapy or meditating.

Guilt and blame

You may feel guilty or blame yourself for the cancer. You may want to find reasons for why it has happened to you.

Most of the time, it is impossible to know exactly what causes a cancer. Over time, a combination of different risk factors may cause a cancer. Doctors do not fully understand all these factors yet. Try to focus on looking after yourself and getting the help and support you need.

Feeling alone

You may feel alone or isolated. This could be because you do not think you have support. Family and friends may live far away, be busy, or feel uncomfortable talking about the cancer. Try to tell your family and friends how you feel. This can help them find ways to support you.

You may have times when you want to be alone for a while. But if you find you are avoiding people a lot of the time, try to talk to your doctor or nurse.

If you need more support, you can call the Macmillan Support Line on **0808 808 00 00** and talk to one of our cancer support specialists. Our website can help you find local support groups. Visit **macmillan.org.uk/supportgroups**

You can also talk to other people affected by cancer on our Online Community. Visit **macmillan.org.uk/community**

If you need more help

You may find it very difficult to cope with your emotions and may need more help. This does not mean you are failing in any way.

Talk to your doctor or nurse if:

- you feel anxious or worried a lot of the time
- you think you may be depressed.

They can refer you to a specialist doctor, psychologist or counsellor who can help. They may also prescribe medicines to help.

We have more information about coping with the emotional effects of cancer in our booklet **How are you feeling? The emotional effects of cancer** (page 130).

> **‘One of the problems us boys have is that we don’t like to ask for help. But Macmillan made you feel as if you weren’t asking for help, or that it was alright to ask for help.’**
>
> **Paul, diagnosed with advanced prostate cancer**

Coping with your emotions

You may feel that the cancer has taken over your life. This is a common reaction. It can be very hard to cope with.

But there are lots of things you can do to help you feel differently:

- You may find it helps to try to keep doing your usual activities.
- You may want to think about what is important to you. This could mean spending time with family, planning a holiday or starting a new hobby.
- You might decide to change your lifestyle. This could be eating healthily, being physically active or trying complementary therapies.
- Making plans can help you feel more in control.
- You might find knowing more about the cancer and your treatment options also helps you cope. It means you can make a plan with your healthcare team.
- Making choices and being active in your own care can help you feel more in control.

If you feel you are not coping well, or need more support, talk to your doctor or nurse.

If you are a family member or friend

If you know someone with cancer, you might find it hard to talk about the cancer or your feelings. You might think it is best to pretend everything is fine. You might not want to worry them. Or you might feel you are letting them down if you admit you are worried or scared.

But not talking to the person with cancer about how you feel may make them feel alone.

You can support the person with cancer by listening and talking with them. Do not feel you have to talk about the cancer. Often it is enough just to listen and let the person with cancer talk when they are ready.

You may find some of the courses on our Learn Zone website helpful. There are courses to help with listening and talking. Visit **macmillan.org.uk/learnzone** to find out more.

We have more information in our booklet **Talking to someone with cancer** (page 130).

If you are looking after a family member or friend with cancer, you may be a carer. We have more information and practical tips for carers on our website.

Talking to children about cancer

Deciding what to tell children about cancer is difficult. It can be hard to know what to tell them, and you may be worried about upsetting them. Children do not always show their feelings, but their behaviour may change at home or at school.

Talking to children about the cancer can:

- help them understand what is going on
- help them feel supported
- prepare them for any changes.

It may also help with some of your own anxiety too. For example, not telling them about hospital appointments may cause extra stress.

How much you tell children will depend on their age and how mature they are. It may be best to start by giving them small amounts of information, and then tell them more when they are ready. Teenagers usually understand what cancer is. Some will want to know more.

Whether they are teenagers or young children, talking about the cancer helps them cope.

Teenagers

It can help to encourage teenagers to ask questions, ask them their opinion and try to give them time to think about what is happening. They may have to, or want to, take on more responsibilities to help – perhaps cooking meals or looking after younger children. This can be hard at a time when they may want more freedom and independence.

Sometimes teenagers may find it hard to talk about a cancer diagnosis. You can encourage them to talk to someone they trust, who can support and listen to them.

This might be a grandparent, family friend, teacher or counsellor. They may also find support online.

We have more information in our booklet **Talking to children and teenagers when an adult has cancer** (page 130).

> ‘The most difficult task my wife and I had was how, when and what are we going to tell the boys?’
>
> **John, diagnosed**
> **with advanced prostate cancer**

WORK AND FINANCIAL SUPPORT

Financial help and benefits

When you are affected by cancer, you might need help with extra costs. Or you might need financial support if you have to stop working.

Statutory Sick Pay

If you work for an employer and take time off sick, you may be able to get Statutory Sick Pay. Your employer will pay this for up to 28 weeks.

Benefits

Benefits are payments from the government to people who need financial help. You can find out more about benefits and apply for them online. Go to **gov.uk** if you live in England, Wales or Scotland, or **nidirect.gov.uk** if you live in Northern Ireland.

Here are some benefits that you might be able to get if you are affected by cancer.

Employment and Support Allowance (ESA)

This benefit is for people under State Pension age who have an illness or disability that affects how much they can work. There are different types of ESA, so it is a good idea to speak to a welfare rights adviser to see if you can make a claim.

Universal Credit

Universal Credit (UC) is a benefit for people under State Pension age who are either:

- out of work – for example, because of an illness or because they are caring for someone
- on a low income.

UC can include money for basic living costs, looking after children and housing.

Personal Independence Payment

This benefit is for people aged 16 to State Pension age who have problems moving around or looking after themselves. You must have had these problems for 3 months and expect them to last for at least 9 months, unless you are terminally ill.

Attendance Allowance

This benefit is for people at or over State Pension age who have problems looking after themselves because of an illness or disability. This could mean problems getting out of bed, having a bath or getting dressed. You must have had these problems for at least 6 months, unless you are terminally ill.

Special rules

If you are terminally ill, you can apply for some benefits using a fast-track process called special rules. You can apply if your doctor thinks you may be reasonably expected to live for less than 12 months. Your claim will be dealt with quickly and you will get the benefit you applied for at the highest rate. It does not matter if you live longer than 12 months. Your doctor or specialist nurse will need to fill out a form for you.

Help for carers

Carer's Allowance is a weekly benefit to help people who look after someone with a lot of care needs. If you do not qualify for it, you may still be able to apply for Carer's Credit.

Carer's Credit helps prevent gaps in your National Insurance record if you have to stop working while you are caring for someone else. You do not get money, but it protects your right to a State Pension later in life.

Grants

You may be able to get some financial help from other charities, for example one-off grants. For further information, contact the Macmillan Support Line on **0808 808 00 00**.

Insurance

If you have, or have had, cancer, you may find it hard to get certain types of insurance. This includes life and travel insurance. A cancer diagnosis might also mean that you can get a payout from an insurance scheme that you already have.

If you are thinking about buying insurance or making a claim, one of our money advisers can help. You can call them on **0808 808 00 00**.

We have more information in our booklet **Travel and cancer** (page 130). Our Online Community forum on **Travel insurance** may also be helpful. Visit **macmillan.org.uk/travelinsurancegroup**

More information

The benefits system and other types of financial support can be hard to understand. Macmillan has experienced money advisers that you can speak to. Call the Macmillan Support Line on **0808 808 00 00**.

You can also get information about benefits and other types of financial help from Citizens Advice (page 140) or Advice NI if you are in Northern Ireland (page 139).

Our booklet **Help with the cost of cancer** has lots more information (page 130).

Work

You may not know how cancer will affect your work, now or in the future.

It is a good idea to talk to your manager soon after you are diagnosed. If your workplace has a human resources (HR) or personnel department, contact them as soon as you can. If they know how the cancer or treatment may affect your ability to work, they can support you better.

Some people stop working during cancer treatment and for a while after, until they feel ready to go back. Others keep working, perhaps with reduced hours or other changes to their job.

Some people may decide not to go back to work. Or they may choose to do something different. Others may not be able to go back to work because of the effects of cancer on their health. Going back to work may depend on the type of work you do or how much your income is affected.

It is important not to do too much, too soon. Your cancer doctor, GP or specialist nurse can help you decide when and if you should go back to work.

Our booklets **Work and cancer**, **Working while caring for someone with cancer** and **Self-employment and cancer** have more information that may be helpful (page 130). There is also lots more information at **macmillan.org.uk/work**

Employment rights

If you have, or have ever had, cancer, the law considers this as a disability. This means you cannot be treated less favourably than people who do not have cancer because you have cancer, or for reasons connected to the cancer. That would be discrimination.

The law also says your employer must make reasonable adjustments (changes) to your workplace and their work practices to help you stay at work or return to work.

If you live in England, Scotland or Wales, you are protected by the Equality Act 2010. If you live in Northern Ireland, you are protected by the Disability Discrimination Act 1995.

Our booklet **Your rights at work when you are affected by cancer** has more information (page 130).

> **‘I was referred to a Macmillan nurse and was also helped financially with 2 grants, 18 months apart. These grants kept me on the road.’**
>
> **Paul, diagnosed with advanced prostate cancer**

FURTHER INFORMATION

About our information

We provide expert, up-to-date information about cancer. And all our information is free for everyone.

Order what you need

You may want to order more booklets or leaflets like this one. Visit **orders.macmillan.org.uk** or call us on **0808 808 00 00**.

We have booklets about different cancer types, treatments and side effects. We also have information about work, financial issues, diet, life after cancer treatment and information for carers, family and friends.

Online information

All our information is also available online at **macmillan.org.uk/information-and-support** You can also find videos featuring stories from people affected by cancer, and information from health and social care professionals.

Other formats

We also provide information in different languages and formats, including:

- audiobooks
- Braille
- British Sign Language
- easy read booklets
- interactive PDFs
- large print
- translations.

Find out more at **macmillan.org.uk/otherformats**

If you would like us to produce information in a different format for you, email us at **informationproductionteam@macmillan.org.uk** or call us on **0808 808 00 00**.

The language we use

We want everyone affected by cancer to feel our information is written for them.

We try to make sure our information is as clear as possible. We use plain English, avoid jargon, explain any medical words, use illustrations to explain text, and make sure important points are highlighted clearly.

We use gender-inclusive language and talk to our readers as ‘you’ so that everyone feels included. Where clinically necessary we use the terms ‘men’ and ‘women’ or ‘male’ and ‘female’. For example, we do so when talking about parts of the body or mentioning statistics or research about who is affected. Our aims are for our information to be as clear and relevant as possible for everyone.

You can read more about how we produce our information at **macmillan.org.uk/ourinfo**

Other ways we can help you

At Macmillan, we know how a cancer diagnosis can affect everything, and we are here to support you.

Talk to us

If you or someone you know is affected by cancer, talking about how you feel and sharing your concerns can really help.

Macmillan Support Line

Our support line is made up of specialist teams who can help you with:

- emotional and practical support if you or someone you know has been diagnosed with cancer
- clinical information from our specialist nurses about things like diagnosis and treatments
- welfare rights advice, for information about benefits and general money worries.

To contact any of our teams, call the Macmillan Support Line for free on **0808 808 00 00**. Or visit **macmillan.org.uk/support-line** to chat online and find the options and opening times.

Macmillan Information and Support Centres

Our Information and Support Centres are based in hospitals, libraries and mobile centres. There, you can speak with someone face to face. Visit one to get the information you need, or if you would like a private chat, most centres have a room where you can speak with someone alone and in confidence.

Find your nearest centre at **macmillan.org.uk/informationcentres** or call us on **0808 808 00 00**.

Talk to others

No one knows more about the impact cancer can have on your life than those who have been through it themselves. That is why we help to bring people together in their communities and online.

Support groups

Whether you are someone living with cancer or a carer, we can help you find support in your local area, so you can speak face to face with people who understand. Find out about support groups in your area by calling us or by visiting **macmillan.org.uk/selfhelpandsupport**

Online Community

Thousands of people use our Online Community to make friends, blog about their experiences and join groups to meet other people going through the same things. You can access it any time of day or night. Share your experiences, ask questions, or just read through people's posts at **macmillan.org.uk/community**

The Macmillan healthcare team

Our nurses, doctors and other health and social care professionals give expert care and support to individuals and their families. Call us or ask your GP, consultant, district nurse or hospital ward sister if there are any Macmillan professionals near you.

Help with money worries

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. If you have been affected in this way, we can help.

Financial guidance

Our financial team can give you guidance on mortgages, pensions, insurance, borrowing and savings.

Help accessing benefits

You can speak to our money advisers for more information. Call us free on 0808 808 00 00. Visit **macmillan.org.uk/financialsupport** for more information about benefits.

Help with work and cancer

Whether you are an employee, a carer, an employer or are self-employed, we can provide support and information to help you manage cancer at work. Visit **macmillan.org.uk/work**

Other useful organisations

There are lots of other organisations that can give you information or support. Details correct at time of printing.

Prostate cancer support organisations

Bladder and Bowel Community

Home Delivery Service **0800 031 5406**

www.bladderandbowel.org

Provides information and advice on a range of symptoms and conditions related to the bladder and bowel, including incontinence, constipation and diverticular disease.

Orchid

Helpline **0808 802 0010**

www.orchid-cancer.org.uk

Funds research into men’s cancers and their diagnosis, prevention and treatment. Offers free information leaflets and fact sheets, and runs an enquiry service supported by Orchid Male Cancer Information Nurses.

Prostate Cancer UK

Helpline **0800 074 8383**

www.prostatecanceruk.org

Provides information and support to men with prostate cancer and their families. Has offices in London, the Midlands, Scotland, Wales and Northern Ireland.

Prostate Scotland

Tel **0131 603 8660**

www.prostatescotland.org.uk

A Scottish charity set up to provide information, advice and support on prostate health and diseases of the prostate. You can watch videos online and download free leaflets and booklets.

Tackle Prostate Cancer

Tel **0800 035 5302**
www.tackleprostate.org
An organisation of UK patient-led prostate cancer support groups.

Support with sexual issues

College of Sexual and Relationship Therapists (COSRT)

Tel **020 8106 9635**
www.cosrt.org.uk
The UK's leading membership organisation for therapists specialising in sexual and relationship issues.

Prostate Cancer UK sexual support service

Specialist nurses **0800 074 8383**
www.prostatecanceruk.org/get-support/sexual-support
A service for you or your partner to talk to a specialist nurse with an interest in helping with sexual problems after treatment for prostate cancer.

Sexual Advice Association

www.sexualadviceassociation.co.uk
Aims to improve the sexual health and well-being of men and women, and to raise awareness of how sexual conditions affect the general population.

General cancer support organisations

Cancer Black Care

Tel **020 8961 4151**
www.cancerblackcare.org.uk
Offers UK-wide information and support for people from Black and minority ethnic communities who have cancer. Also supports their friends, carers and families.

Cancer Research UK

Helpline **0808 800 4040**
www.cancerresearchuk.org
A UK-wide organisation that has patient information on all types of cancer. Also has a clinical trials database.

Macmillan Cancer Voices

www.macmillan.org.uk/cancervoices
A UK-wide network that enables people who have or have had cancer, and those close to them such as family and carers, to speak out about their experience of cancer.

Maggie's

Tel **0300 123 1801**
www.maggies.org
Has a network of centres in many locations throughout the UK. Provides free information about cancer and financial benefits. Also offers emotional and social support to people with cancer, their family, and friends.

Penny Brohn UK

Helpline **0303 3000 118**
www.pennybrohn.org.uk
Offers physical, emotional and spiritual support across the UK, using complementary therapies and self-help techniques.

Tenovus

Helpline **0808 808 1010**
www.tenovuscancercare.org.uk
Aims to help everyone in the UK get equal access to cancer treatment and support. Funds research and provides support such as mobile cancer support units, a free helpline, benefits advice and an online 'Ask the nurse' service.

Counselling

British Association for Counselling and Psychotherapy (BACP)

Tel **0145 588 3300**
www.bacp.co.uk
Promotes awareness of counselling and signposts people to appropriate services across the UK. You can also search for a qualified counsellor on the 'How to find a therapist' page.

UK Council for Psychotherapy (UKCP)

Tel **020 7014 9955**
www.psychotherapy.org.uk
Holds the national register of psychotherapists and psychotherapeutic counsellors, listing practitioners who meet exacting standards and training requirements.

Emotional and mental health support

Mind

Helpline **0300 123 3393**
www.mind.org.uk
Provides information, advice and support to anyone with a mental health problem through its helpline and website.

Samaritans

Helpline **116 123**
Email **jo@samaritans.org**
www.samaritans.org
Provides confidential and non-judgemental emotional support, 24 hours a day, 365 days a year, for people experiencing feelings of distress or despair.

Financial support or legal advice and information

Advice NI

Helpline **0800 915 4604**
www.adviceni.net
Provides advice on a variety of issues including financial, legal, housing and employment issues.

Benefit Enquiry Line Northern Ireland

Helpline **0800 232 1271**
Textphone **028 9031 1092**
www.nidirect.gov.uk/money-tax-and-benefits
Provides information and advice about disability benefits and carers' benefits in Northern Ireland.

Carer's Allowance Unit

Tel **0800 731 0297**
Textphone **0800 731 0317**
www.gov.uk/carers-allowance
Manages state benefits in England, Scotland and Wales. You can apply for benefits and find information online or through its helplines.

Citizens Advice

Provides advice on a variety of issues including financial, legal, housing and employment issues. Use its online webchat or find details for your local office by contacting:

England

Helpline **0800 144 8848**
www.citizensadvice.org.uk

Scotland

Helpline **0800 028 1456**
www.cas.org.uk

Wales

Helpline **0800 702 2020**
www.citizensadvice.org.uk/wales

Civil Legal Advice

Helpline **0345 345 4345**
Textphone **0345 609 6677**
www.gov.uk/civil-legal-advice

Has a list of legal advice centres in England and Wales and solicitors that take legal aid cases. Offers a free translation service if English is not your first language.

GOV.UK

www.gov.uk

Has information about social security benefits and public services in England, Scotland and Wales.

Law Centres Network

www.lawcentres.org.uk

Local Law Centres provide advice and legal assistance. They specialise in social welfare issues including disability and discrimination.

Local councils (England, Scotland and Wales)

Your local council may have a welfare rights unit that can help you with benefits. You can also contact your local council to claim Housing Benefit and Council Tax Reduction, education benefits, and for help from social services (the Social Work department in Scotland).

You should be able to find your local council's contact details in your phone book or visit:

England
www.gov.uk/find-local-council

Scotland
www.cosla.gov.uk/councils

Wales
gov.wales/find-your-local-authority

Macmillan Benefits Advice Service (Northern Ireland)
Tel **0300 1233 233**

Money Advice Scotland
www.moneyadvicescotland.org.uk
Use the website to find qualified financial advisers in Scotland.

NI Direct
www.nidirect.gov.uk
Has information about benefits and public services in Northern Ireland.

Northern Ireland Housing Executive
Tel **03448 920 902**
www.nihe.gov.uk
Offers help to people living in socially rented, privately rented and owner-occupied accommodation.

StepChange Debt Charity
Tel **0800 138 1111**
www.stepchange.org
Provides free debt advice through phone, email, the website and online through live chats with advisers.

Unbiased.co.uk

Helpline **0800 023 6868**
www.unbiased.co.uk
You can search the website for qualified advisers in the UK who can give expert advice about finances, mortgages, accounting or legal issues.

LGBT-specific support

LGBT Foundation

Tel **0345 330 3030**
lgbt.foundation
Provides a range of services to the LGBT community, including a helpline, email advice and counselling. The website has information on various topics including sexual health, relationships, mental health, community groups and events.

OUTpatients (formerly called Live Through This)

www.outpatients.org.uk
A safe space for anybody who identifies as part of the queer spectrum and has had an experience with any kind of cancer at any stage. Also produces resources about LGBT cancer experiences. OUTpatients runs a peer support group with Maggie's Barts.

Support for carers

Carers Trust

Tel **0300 772 9600**
www.carers.org
Provides support, information, advice and services for people caring at home for a family member or friend. You can find details for UK offices and search for local support on the website.

Carers UK

Helpline **0808 808 7777**
www.carersuk.org
Offers information and support to carers across the UK. Has an online forum and can put people in contact with local support groups for carers.

Cancer registries

The cancer registry is a national database that collects information on cancer diagnoses and treatment. This information helps the NHS and other organisations plan and improve health and care services.

There is a cancer registry in each country in the UK. They are run by the following organisations:

England – National Disease Registration Service (NDRS)

www.digital.nhs.uk/ndrs/patients

Scotland – Public Health Scotland (PHS)

www.publichealthscotland.scot/our-areas-of-work/conditions-and-diseases/cancer/scottish-cancer-registry-and-intelligence-service-scris/overview

Wales – Welsh Cancer Intelligence and Surveillance Unit (WCISU)

Tel **0292 010 4278**
www.phw.nhs.wales/wcisu

Northern Ireland – Northern Ireland Cancer Registry (NICR)

Tel **0289 097 6028**
www.qub.ac.uk/research-centres/nicr/AboutUs/Registry

Disclaimer

Thanks

This booklet has been written, revised and edited by Macmillan Cancer Support's Cancer Information Development team. It has been approved by Senior Medical Editor, Dr Lisa Pickering, Consultant Medical Oncologist.

With thanks to: Indu Francis, Clinical Nurse Specialist and Surgical Nurse Practitioner; Dr John Frew, Consultant Clinical Oncologist; Dr Debra Josephs, Consultant Medical Oncologist; and Dr Elias Pintus, Consultant Medical Oncologist.

Thanks also to the people affected by cancer who reviewed this edition, and those who shared their stories.

We welcome feedback on our information. If you have any, please contact **informationproductionteam@macmillan.org.uk**

Sources

Below is a sample of the sources used in our advanced prostate cancer information. If you would like more information about the sources we use, please contact us at **informationproductionteam@macmillan.org.uk**

Horwich A et al. ESMO Consensus Guidelines: Prostate cancer. Annals of Oncology. 2012.
The National Institute for Health and Care Excellence (NICE). Prostate cancer: diagnosis and management. NICE Guidelines. May 2019.

Your notes and questions

Can you do something to help?

We hope this booklet has been useful to you. It is just one of our many publications that are available free to anyone affected by cancer. They are produced by our cancer information specialists who, along with our nurses, benefits advisers, campaigners and volunteers, are part of the Macmillan team. When people are facing the toughest fight of their lives, we are here to support them every step of the way.

We want to make sure no one has to go through cancer alone, so we need more people to help us. When the time is right for you, here are some ways in which you can become a part of our team.

5 ways you can help someone with cancer

Share your cancer experience
Support people living with cancer by telling your story, online, in the media or face to face.

Campaign for change
We need your help to make sure everyone gets the right support. Take an action, big or small, for better cancer care.

Help someone in your community
A lift to an appointment. Help with the shopping.
Or just a cup of tea and a chat. Could you lend a hand?

Raise money
Whatever you like doing you can raise money to help.
Take part in one of our events or create your own.

Give money
Big or small, every penny helps.
To make a one-off donation see over.

Call us to find out more 0300 1000 200
macmillan.org.uk/getinvolved

Please fill in your personal details

Mr/Mrs/Miss/Other

Name

Surname

Address

Postcode

Phone

Email

Please accept my gift of £
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I enclose a cheque / postal order / Charity Voucher made payable to Macmillan Cancer Support
OR debit my:
Visa / MasterCard / CAF Charity Card / Switch / Maestro

Card number

Valid from **Expiry date**

Issue no **Security number**

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Date / /

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Do you pay tax? If so, your gift will be worth 25% more to us – at no extra cost to you. All you have to do is tick the box below, and the tax office will give 25p for every pound you give.

☐ I am a UK tax payer and I would like Macmillan Cancer Support to treat all donations I make or have made to Macmillan Cancer Support in the last 4 years as Gift Aid donations, until I notify you otherwise.

I understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference. I understand Macmillan Cancer Support will reclaim 25p of tax on every £1 that I give.

Macmillan Cancer Support and our trading companies would like to hold your details in order to contact you about our fundraising, campaigning and services for people affected by cancer. If you would prefer us not to use your details in this way please tick this box. ☐

In order to carry out our work we may need to pass your details to agents or partners who act on our behalf.

If you would rather donate online go to **macmillan.org.uk/donate**

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Please cut out this form and return it in an envelope (no stamp required) to: Freepost RUCY-XGCA-XTHU, Macmillan Cancer Support, PO Box 791, York House, York YO1 0NJ

MACMILLAN
CANCER SUPPORT

This booklet is about advanced prostate cancer. It is for anyone who has been diagnosed with advanced prostate cancer. There is also information for carers, family members and friends.

The booklet talks about the signs and symptoms of advanced prostate cancer. It explains how it is diagnosed and how it may be treated. It also has information about emotional, practical and financial issues.

At Macmillan we know cancer can disrupt your whole life. We'll do whatever it takes to help everyone living with cancer in the UK get the support they need right now, and transform cancer care for the future.

For information, support or just someone to talk to, call **0808 808 00 00** or visit **macmillan.org.uk**

Would you prefer to speak to us in another language? Interpreters are available. Please tell us in English the language you would like to use. Are you deaf or hard of hearing? Call us using Relay UK on **18001 0808 808 00 00**, or use the Relay UK app.

Need information in different languages or formats? We produce information in audio, interactive PDFs, easy read, Braille, large print and translations. To order these, visit **macmillan.org.uk/otherformats** or call our support line.

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